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ABSTRACT

This collection of 10 papers addresses "best practices" in the development of transition services for youths who are deaf-blind. The papers include quality indicators checklists, transition planning checklists, and other assessment tools. The papers have the following titles and authors: "Overview of Transition Services for Youths Who Are Deaf-Blind" (Jane M. Everson); "Including Transition Services in the IEPs of Youths Who Are Deaf-Blind" (Jane M. Everson and Joan Houghton); "Communication Instruction and Supports for Transition-Age Youths Who Are Deaf-Blind" (deVergne Goodall); "Addressing the Medical and Health Issues of Transition-Age Youths Who Are Deaf-Blind" (Theresa Carr and Joan Houghton); "Orientation and Mobility for Transition-Age Youths Who Are Deaf-Blind" (Joan Houghton); "Developing Employment Opportunities for Youths Who Are Deaf-Blind" (Janet Steveley and others); "Developing Recreation and Leisure Time Opportunities for Youths Who Are Deaf-Blind" (Kathleen McNulty); "Postsecondary Education Opportunities for Youth Who Are Deaf-Blind" (JoAnn Enos); "Expanding Social Opportunities for Youths Who Are Deaf-Blind" (JoAnn Enos); and "Family Involvement in the Transition Process for Youths Who Are Deaf-Blind" (Kathleen McNulty). (Each chapter contains references.) (JDD)

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ED 380 935

TRANSITION SERVICES FOR YOUTHS WHO ARE DEAF-BLIND: A "BEST PRACTICES" GUIDE FOR EDUCATORS

JANUARY, 1995
THE HELEN KELLER NATIONAL CENTER - TECHNICAL ASSISTANCE CENTER

Jane M. Everson, Ph.D.
Editor

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CHAPTER ONE

Overview of Transition Services for Youths Who Are Deaf-Blind

☞ *by Jane M. Everson*

WHAT ARE TRANSITION SERVICES?

- "...a coordinated set of activities for a student...including postsecondary education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living and/or community participation" [PL 101-476, 20 U.S.C. 1401 (a) (19)].

- This coordinated set of activities must include: (i) instruction; (ii) community experience; (iii) employment and other postsecondary adult living objectives, and (iv) if appropriate, acquisition of daily living skills and functional vocational evaluation.

- A statement of needed transition services must be included within the IEPs of all youths beginning no later than age 16 "...including a statement of each public agency's and each participating agency's responsibilities and linkages...If the IEP determines that services are not needed in one or more of the areas specified...the IEP must include a statement to that effect and the basis upon which the determination was made..." [PL 101-476, 20 U.S.C. 1401 (a) (20); 1412 (b) (2); 1414 (a) (5)].

- Parents and their child must be notified and invited to transition planning meetings.

- Representatives from any other agency that is likely to be responsible for providing or paying for transition services must be invited to the meeting.

- Transition services identified in the IEP must include instruction, community experiences, and the development of employment and other postschool adult living objectives. If one or more of these areas is not addressed, the IEP must indicate why the area or areas were not selected.

- Since the statement of transition services is part of the IEP, the IEP team must consider it at least annually and it is subject to all the regulations and policies governing the IEP.

Why are Transition Services so Important for Youths Who Are Deaf-Blind?

- Nationally, there are an uncertain number of deaf-blind youths and adults. A reported 7,839 children and youths between birth and age 21 experience dual sensory impairment with an expected count of 7,657 and 12,274 (Baldwin, 1992).

- Although many follow-up studies of former special education youths were conducted during the 1980s, only two attempted to isolate and address the specific transition experiences of youths who are deaf-blind (e.g., Frey, 1988; Wagner, 1993). These studies indicate that youths who are deaf-blind and youths who are multi-handicapped experience the poorest transition outcomes of all youths with disabilities.

Findings of the National Transition Study Related to Youths Who Are Deaf-Blind (Wagner, 1993)

- Of a sample size of 31 deaf-blind youths, only 13.4% transitioned from school to vocational or trade schools and 8.9% of youths transitioned to two-year or four-year colleges. Of a sample size of 99 multiply handicapped youths, only .7% transitioned from school to vocational or trade schools and 7.9% and 2.2% transitioned to two-year or four-year colleges respectively.

- Of a sample size of 34 youths labelled deaf-blind, only 19.2% transitioned from school to competitive employment. Of a sample size of 111 multiply handicapped youths, only 14.8% transitioned from school to competitive employment.

- Of a sample size of 34 deaf-blind youths, only 2.9% were living independently after leaving school. Of a sample size of 114 multiply handicapped youths, only 5.9% were living independently.

Results of the Michigan Department of Education Follow-Up Study of Youths Who Are Deaf-Blind (Frey, 1988)

- Of a sample size of 30 deaf-blind adults, seven (23%) lived at home; seven (23%) lived in a group home; and 16 (54%) lived in an institution or nursing home.

- Not one individual residing in an institution or nursing home reported having a single close personal friend, yet 43% of those individuals living in less restrictive environments reported having at least one close personal friend.

- Seven individuals worked for pay; two individuals held non-paid, volunteer positions. All seven individuals working for pay were employed approximately 30 hours per week.

What "Best Practices" are Associated with Transition Services?

- They are trandisciplinary and interagency in nature. They include roles for education, related services, and adult services personnel both in the development and the implementation of the transition services plan.

- They are youth- and family-centered. Youths and families must play a role both in the development and implementation of the plan. Person-centered planning approaches (e.g., personal futures planning) are one effective way to accomplish this.

- They are visionary and outcome-oriented. Transition services are driven by the future needs and wants of the youth and family -- not by the services and outcomes currently available. The use of a structured transition planning document, the provision of parent and family training, youth self-advocacy activities, personal futures planning activities, and state- and local-level interagency teams may all be used to supplement traditional IEP activities and enhance achievement of visionary transition outcomes.

What "Best Practices" are Associated With Transition Services Specifically for Youths Who Are Deaf-Blind?

- Quality transition services for youths who are deaf-blind are characterized much the same as transition services for other youths with severe and multiple disabilities. Transition services prepare youths and their families for the challenges and opportunities of adult life. They support young adults and their families in a variety of community-inclusive postsecondary education, employment, recreation, and community living opportunities. However, there are some specific quality indicators that transition planning teams should consider when developing and implementing the transition services component of the IEP for youths who are deaf-blind, Table 1.1.

TABLE 1.1

Quality Indicators of Transition Services for Youths Who Are Deaf-Blind	
✓	Does the IEP/statement of transition services identify regularly-scheduled activities which support a youth's participation in environments that adults without disabilities engage in on a daily basis in their: (a) homes, (b) workplaces, (c) recreational settings, (d) schools, and (e) other community settings?
✓	Does the IEP/statement of transition services specify that individualized communication systems and supports are infused within all daily environments, activities, and interactions?
✓	Does the IEP/statement of transition services specify that all activities and materials are adapted (as needed) to support tactual and/or low vision needs?
✓	Does the IEP/statement of transition services specify that all activities, materials, and environments are adapted (as needed) to support individualized sound-dampening and sound-enhancing needs?
✓	Does the IEP/statement of transition services specify that all activities, materials and environments support (as needed) individualized orientation and mobility (O & M) needs?
✓	Does the IEP/statement of transition services specify that the youth has and correctly uses (as needed) assistive technology such as communication aids, mobility aids, hearing aids, assistive listening devices, and/or low vision aids?
✓	Are individualized task analyses, systematic instructional procedures and data collection procedures in place for classroom and community activities?

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CHAPTER TWO

Including Transition Services in the IEPs of Youths Who Are Deaf-Blind

☞ by Jane M. Everson and Joan Houghton

WHAT ARE THE STEPS IN DEVELOPING IEPS WHICH INCLUDE STATEMENTS OF TRANSITION SERVICES?

▸ Numerous transition services models and implementation manuals over the past 10 years have outlined step-by-step processes for developing and implementing individualized transition plans. The steps below, adapted from these materials, provide service providers and families with a process that endorses the basic components of any state or school district's planning processes, but also acknowledge the unique needs of a low-incidence, severely disabled population of youth, such as youths who are deaf-blind.

- **Step One: Identify All Youths Age 14 and Older**
  - ✓ Compile district-level and building-level lists of youths age 14 and older.
  - ✓ Conduct screenings for Usher syndrome for youths who are congenitally deaf or hard-of-hearing if the etiology is unknown.
  - ✓ Consider procedures, roles, and timelines for the transition of youths from out-of-district placements back to their home communities.

- **Step Two: Compile and Update Assessment Records and Information**
  - ✓ Update vision and hearing assessments -- look for functional implications of sensory losses.
  - ✓ Consider alternatives to standardized assessments -- "mapping," functional profiles, situational assessments, etc.

- **Step Three: Identify Appropriate School and Adult Service Personnel to Attend IEP/Transition Planning Meetings**
  - ✓ Define roles for related services -- O&M specialists, communication therapists, low vision specialists, audiologists, etc.
  - ✓ Define roles for adult services -- rehabilitation counselors, case managers, rehabilitation teachers, postsecondary educators, job coaches, etc.

- **Step Four: Invite Parents, Family Members, and Youths**
  - ✓ Encourage self-advocacy activities among youths who are deaf-blind.
  - ✓ Provide pre-meeting training, surveys, mapping activities, and support to ensure equal roles.
  - ✓ Define roles and encourage development of future visions.

- **Step Five: Hold IEP/Transition Planning Meetings**
  - ✓ Begin meeting by discussing the youth and family's desired transition outcomes (e.g., future vision map).
  - ✓ Use structured transition planning document and step-by-step procedures to address all areas of adult life.
  - ✓ Identify interagency and transdisciplinary action steps.
  - ✓ Identify the relationships between desired transition outcomes and IEP goals.
  - ✓ Allow future vision to guide IEP and transition goals, and objectives.

- **Step Six: Implement the IEP/Statement of Transition Services**
  - ✓ Use a transdisciplinary approach.
  - ✓ Use an interagency approach.
  - ✓ Define action steps and timelines for all service providers, family, and youth.

- **Step Seven: Monitor and Evaluate the IEP/Statement of Transition Services**
  - ✓ Update at least annually.
  - ✓ Schedule final IEP meeting as an "exit" meeting to ensure transition of paperwork, files, and responsibilities to adult services, family, and youth.
  - ✓ Include follow-up and follow-along mechanisms and defined responsibilities.

WHAT IS PERSON-CENTERED PLANNING?

▸ Person-centered planning is an umbrella term used here to describe the work of Beth Mount, John O'Brien and others in the United States and Marsha Forest and Judith Snow in Canada. Specific person-centered planning approaches are also known as personal futures planning (Mount & Zwernik, 1988) and MAPS or the McGill Action Planning System (Vandercook, York, & Forest, 1989). Person-centered approaches can be used to enhance more traditional and system-centered service plans, such as IEPs and statements of transition services as mandated by IDEA.

- All person-centered planning approaches begin with a focus on the wants and needs of an individual and recognize the importance of both formal and informal supports in assisting the person in achieving his or her dreams. O'Brien (1987) summarizes three characteristics of all person-centered planning approaches: (1) everyday activities should be the focus of planning efforts; (2) services are less important than family and community connections; and (3) no single person can or should do everything.

- Personal futures planning, because of its focus on future visions and planning activities, is most closely associated with IDEA's mandates and the goals of transition planning. Personal futures planning consists of three components: (1) development of a personal profile and a future vision map; 2) a planning team or "circle of support;" and (3) an action plan (Mount & Zwernik, 1988).

- Personal futures planning is not intended to replace the transition services component of the IEP. Instead, person-centered planning activities can be used to enhance more traditional and system-centered planning services by guiding teams in using, gathering and managing assessment data, developing future goals, and creating packages of supports that are more person-centered and more visionary.

How can Personal Futures Planning Activities be Used to Enhance Traditional IEP/ Transition Planning Activities?

- **Convene a Circle of Support around a Focus Person** - When a "focus person" who is deaf-blind reaches age 14-16, family members may wish to develop a "circle of support." A circle of support is made up of the youth, other family members, friends, neighbors and other community members who have a relationship with the focus person along with the education and adult service providers who are members of the youth's IEP team. This team will meet separately from the IEP team and will engage in some activities that will enhance, but not replace traditional IEP activities.

  Define a role for the focus person to play in the circle, for example, to issue invitations for people to attend circle meetings, to participate by communicating dreams and fears, to assist with developing and displaying maps, etc.

Invite all members to one or two circle meetings prior to the first IEP meeting during which transition services will be discussed. At these meetings, develop a series of maps, known as a personal profile along with a future vision for the youth.

- **Use Personal Profile and Future Vision Maps to Update and Compile IEP Assessment and Planning Data** - One or more of the circle members will also be IEP team members, for example the parents and teachers. These individuals should bring the personal profile and future vision maps to all subsequent IEP meetings and describe them to the rest of the team. Maps should be displayed at all IEP meetings and used to focus discussion on annual goals, objectives, and activities.

  One effective strategy for using the maps to direct IEP activities in a more person-centered way is to open the IEP meeting with a discussion of the youth's future vision. As IEP goals and objectives are developed, team members should ensure that they will assist the youth in achieving his or her desired future vision. For example, will these IEP goals and objectives assist the youth in achieving the desired future vision?

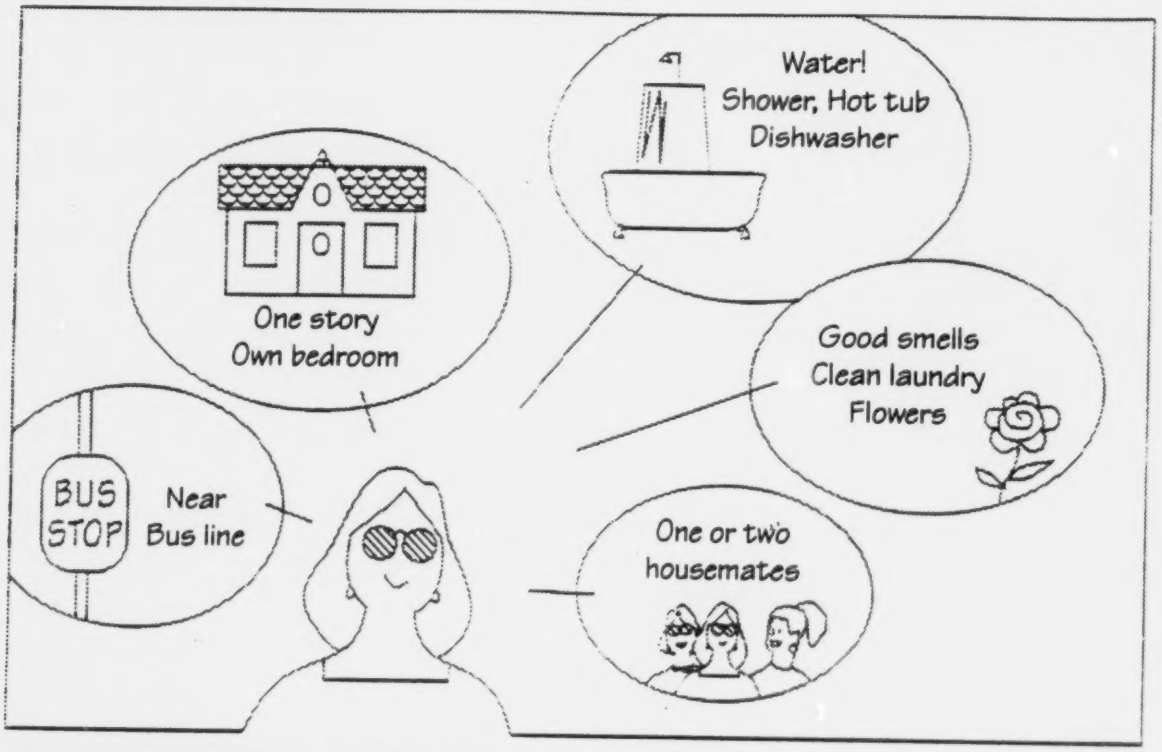
- **Identify Desired Transition Outcomes and Supports to Achieve the Future Vision** - Each area of adult life identified in the statement of transition services (e.g., employment, postsecondary education, living arrangements, homemaking activities, transportation, medical and health supports, recreation, friendships, etc.) should be considered and briefly discussed in relation to the youth's desired future vision. Most of these transition services areas have closely related maps which can be used to update assessment data and present it in a more functional, person-centered and future-oriented way.

- **Develop Related IEP Annual Goals and Short-Term Objectives** - Person-centered assessment and future vision maps allow IEP goals and objectives to naturally follow. Related IEP goals and objectives thus become both family-and person-centered. They become individualized to the personal profiles and future visions of each focus person. For example, Michael's future vision identifies supported employment in a two to three person group model in the area of janitorial services. A related long-term goal might be: Michael will demonstrate janitorial skills in a community-based training site. A related IEP short-term objective might be: Michael will polish brass for 30 minutes with 90% accuracy according to a task analysis for 5 out of 7 consecutive days.

- **Develop and Implement a Team Action Plan to Achieve the Future Vision and Implement the IEP** - Two significant differences between an IEP team and a circle of support are: (1) circles of support meet more frequently than IEP teams; and (2) circles make a long-term commitment to acting as a team in assisting the focus person in achieving a future vision. Some team members may decide they are only willing to create personal profile maps and future vision maps and use them to develop more person-centered IEPs. Others may decide to continue circle activities in order to tackle the systemic issues that may arise from implementation of a youth's future vision. It is important for all team members to assess their connections and commitment to the focus person and define roles with which they are comfortable. Achieving one's future vision is hard, time-consuming work--it may not be a desired role for all service providers, family members or youths.

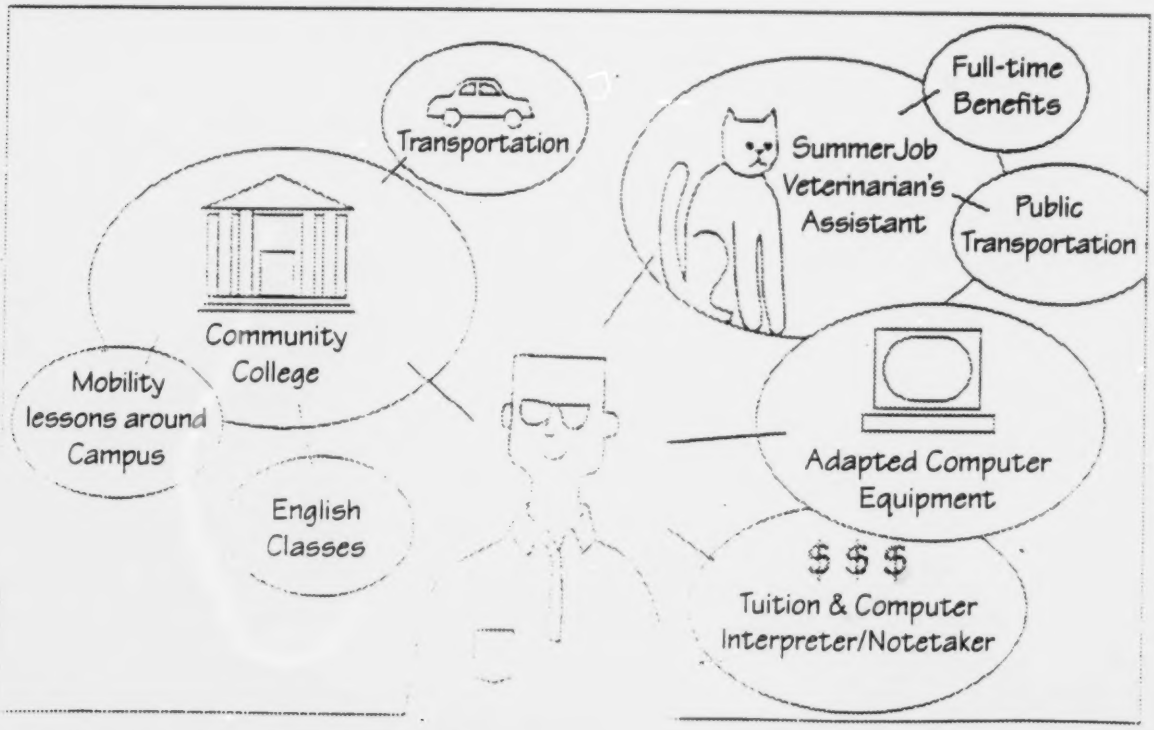
What Are Some Examples of Maps That Have Been Developed For Transition-Age Youths Who Are Deaf-Blind?

Nina's Future Vision Map: Home



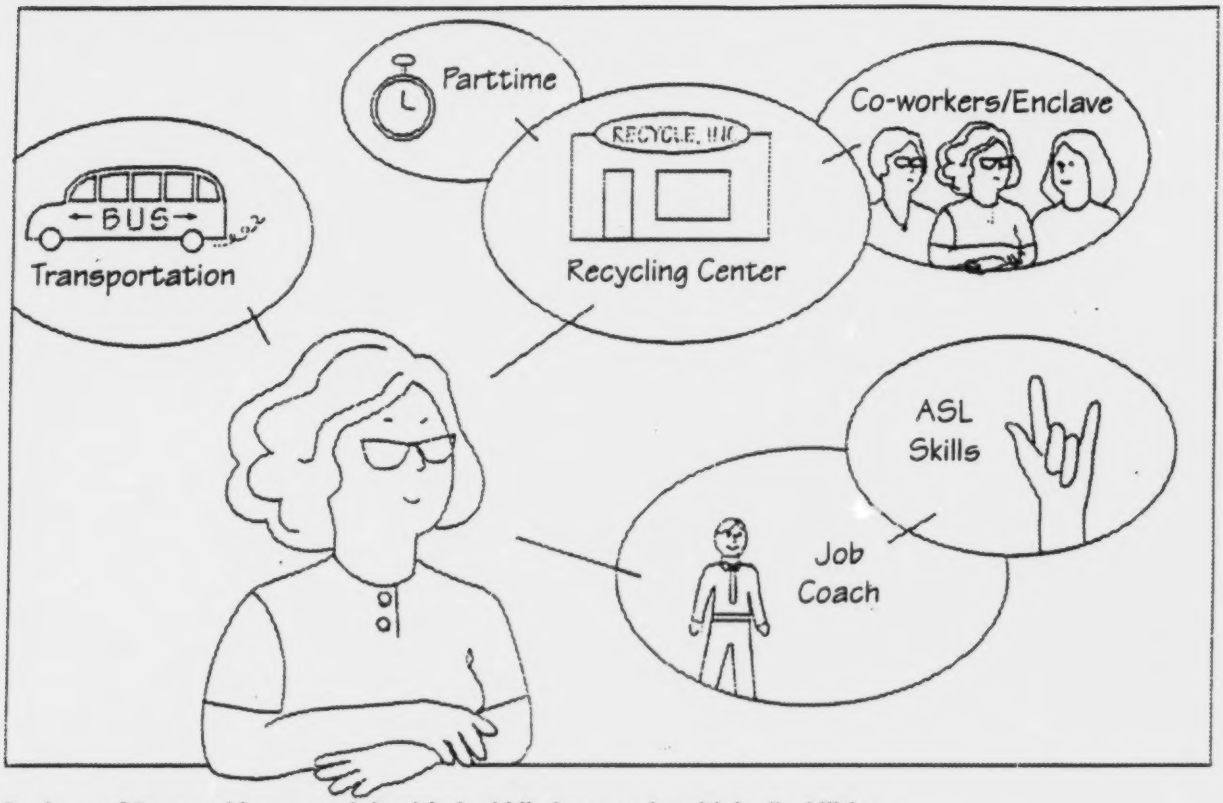
Nina, a 20-year old young adult with deaf-blindness and multiple disabilities

Joel's Future Vision Map: Higher Education



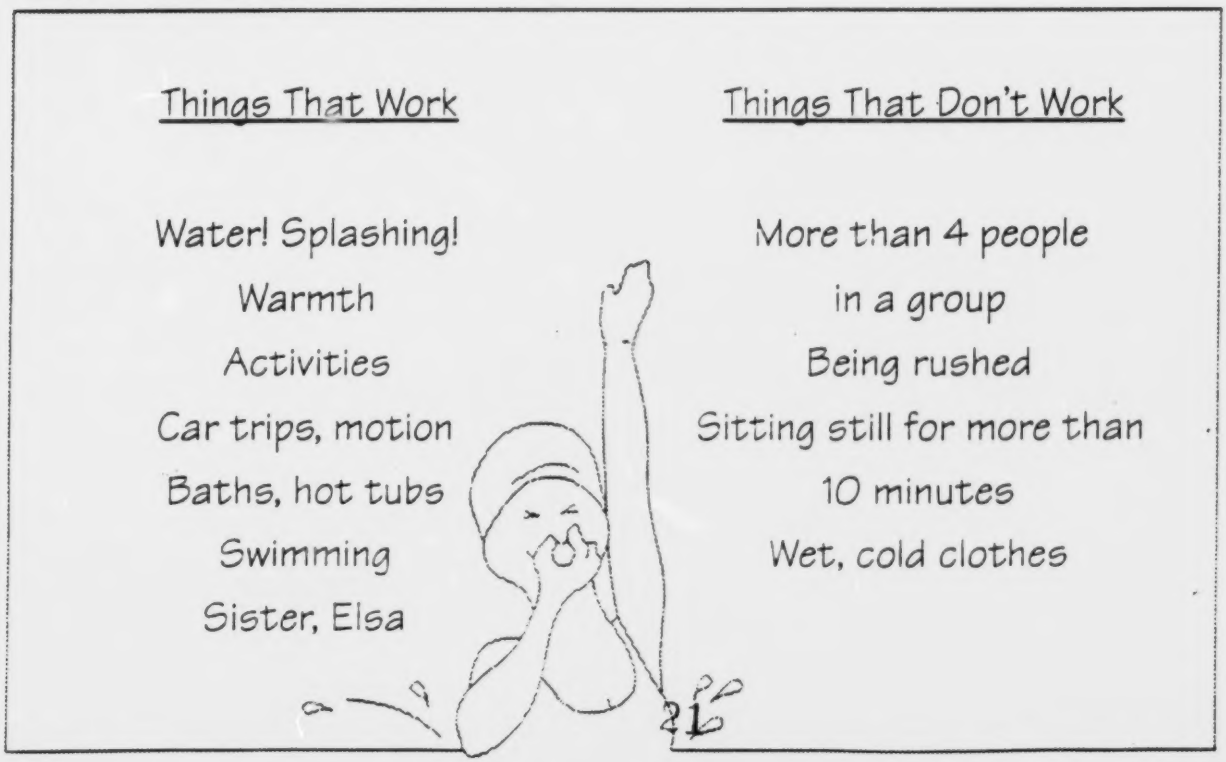
Joel, a 20-year old young adult with deaf-blindness

Regina's Future Vision Map: Employment



Regina, a 20-year old young adult with deaf-blindness and multiple disabilities

Jenny's Preferences Map



Jenny, an 18-year old young adult with deaf-blindness and multiple disabilities

WHAT IS THE DIFFERENCE BETWEEN PERSONAL FUTURES PLANNING AND TRADITIONAL TRANSITION PLANNING?

TABLE 2.1

TRADITIONAL TRANSITION PLANNING	PERSONAL FUTURES PLANNING
A team of service providers meet annually or more frequently as needed with the parents and youth to develop a plan for educational and related services.	A circle of support made up of the focus person with a disability, parents, and other family members meets with service providers and general community members monthly or as frequently as needed to develop a future vision for the focus individual and implement an action plan to achieve the future vision.
A transdisciplinary team conducts and interprets assessment data using standardized and non-standardized assessment mechanisms.	A circle of support gathers, organizes, and manages assessment information into a personal profile and future vision using highly visual graphics known as maps.
The youth with a disability is invited to participate in the team meeting as appropriate.	The circle defines a role for every focus person and assists the person in assuming the roles in a respected and competent manner.
Parents are invited to participate in the development of the individualized service plan.	Parents, other family members, friends, and general community members define the personal profile and future vision and look to service providers for support.
An IEP with a statement of needed transition services is mandated to guide outcomes and support services.	A future vision and action plan guide the circle's activities and should be used to drive IEP/transition plan content.
Implementation of the plan is ensured through provision of entitlement services, due process, and professional services.	Implementation of the plan depends upon the commitment and energy of the circle of support and their connections with the focus person and family.

How Can I choose a More Person-Centered Transition Planning Form?

- Across the United States, numerous forms for developing statements of transition services are available - some are infused within IEP forms, others are addenda statements to IEP forms. A form can be an important component of person-centered transition planning activities because it can help guide a team through a discussion of assessment data, desired adult outcomes, and individualized supports needed to achieve the adult outcomes. Service providers and family members may want to evaluate the transition plan form they are currently using with this checklist, Table 2.2.

TABLE 2.2
IEP/TRANSITION PLANNING FORM:
Choosing and Evaluating a Form

(This checklist can be completed by Teachers, Parents, Support Staff, Students, Administrators and/or Adult Services Providers.)

		Poor 1	2	Average 3	4	Good 5
1.	The form lists outcome areas identified by IDEA (i.e., postsecondary education, vocational training, integrated employment, continuing adult education, adult services, independent living, and community participation).	1	2	3	4	5
2.	The form includes these plus a more exhaustive set of outcome areas (e.g., living arrangements, homemaking needs, transportation, medical, relationships, financial, leisure/recreation and advocacy/legal).	1	2	3	4	5
3.	The form includes space for the team to write/ expand information on individualized adult outcomes.	1	2	3	4	5
4.	The form includes space for the team to define school action steps.	1	2	3	4	5
5.	The form includes space for the team to define adult service action steps.	1	2	3	4	5
6.	The form includes space for the team to define family action steps.	1	2	3	4	5
7.	The form includes space for the team to identify timelines for completion of action steps.	1	2	3	4	5
8.	The form includes space for identifying why one or more outcome areas was not addressed.	1	2	3	4	5
9.	The form shows the relationship between IEP goals and transition services outcomes.	1	2	3	4	5
10.	The form invites family/student participation and dreaming.	1	2	3	4	5

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What is an Example of a Person-Centered Form that May be Used for Developing IEPs with Transition Services?

- Table 2.3, on the following pages, is one example of a form that may be used to develop a statement of transition services for a youth who is deaf-blind. Comprehensive transition planning should consider each of the areas included in Table 2.3.

TABLE 2.3
INDIVIDUALIZED STATEMENT OF TRANSITION SERVICES

Check each area addressed for a youth in each year's plan. For any areas not addressed, indicate the reason.

1. ☐ Postsecondary Education
2. ☐ Employment
3. ☐ Living Arrangements
4. ☐ Homemaking Needs
5. ☐ Financial/Income Needs
6. ☐ Community Resources
7. ☐ Recreation and Leisure
8. ☐ Transportation Needs
9. ☐ Medical Services
10. ☐ Relationships
11. ☐ Advocacy/Legal Needs
12. ☐ Other _____

→ *We, the undersigned, have participated in this transition statement and support its intent and recommendations.*

Student: SS#:	School System:
Parent/Guardian:	Related Service Provider(s):
Teacher:	
ITP Coordinator:	Adult Service Provider(s):

Area	Desired Adult Outcomes	School Action Steps	Date	Family Action Steps	Date	Adult Agency Action Steps	Date

Statement of Transition Services, Continued Student: _____ SS#: _____

Area	Desired Adult Outcomes	School Action Steps	Date	Family Action Steps	Date	Adult Agency Action Steps	Date

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What Are Some Examples Of Transition Outcomes And IEP Annual Goals And Short-Term Objectives That Might Be Included In A Plan For A Youth Who Is Deaf-Blind?

- **Employment Future Vision:**
  Regina will be employed at a recycling business using an enclave supported employment approach by the time she leaves high school.

  → **Annual Goal:**
  - ✓ Regina will demonstrate recycling skills in a community-based training site.

  → **Short-Term Objective:**
  - ✓ Regina will participate in a 15-week community-based work experience (3 days a week, 2 hours a day) where she will learn to sort glass, aluminum, cardboard, and newspaper using tactual/signed cues. She will sort with 90% accuracy according to task analyses for each task across 15 minutes testing sessions.

  → **Interagency Linkages and Responsibilities:**
  - ✓ The special education teacher will establish a group community-based non-paid work experience site at the local recycling business (following U.S. Department of Labor regulations) and provide instruction to Regina and three of her classmates. Instruction will include developing task analyses, identifying tactual/signed cues, and providing systematic instruction for each task.
  - ✓ The rehabilitation counselor will visit Regina at the work experience site at least once to review production data collected by the special education teacher, determine additional assessment need, suggest potential use of rehabilitation technology, and review job development and placement plans.

- **Recreation Future Vision:**
  Jenny will be a member of the community college health and fitness center and will go swimming there with a family member or friend on a weekly or more frequent basis.

  → **Annual Goal:**
  - ✓ Jenny will practice swimming in a community-based swimming program.

→ **Short-Term Objective:**

- ✓ Jenny will go swimming at the local YWCA for 30 minutes once every two weeks with three classmates.

→ **Interagency Linkages and Responsibilities:**

- ✓ The special education teacher will provide tactual/signed instruction in dressing and undressing in the locker room, swimming, and using a life jacket.
- ✓ Jenny's family will enroll her in the community college health and fitness club and take her swimming on a bi-weekly basis.
- ✓ Jenny's family and case manager will explore availability of a peer support person to assist Jenny with transportation, dressing/undressing, swimming, and communicating with the general public.

▸ **Community Living Future Vision:**

Nina will live in a supported home in a neighborhood no more than 30 miles from her parents with no more than two other young adults who can communicate with her.

→ **Annual Goal:**

- ✓ Nina will demonstrate daily living skills in a community living site.

→ **Short-Term Objective:**

- ✓ (Five days a week, two hours a day,) Nina will learn to prepare a simple breakfast and lunch, fold her laundry, unload a dishwasher, and mop a floor with 90 % accuracy according to task analyses at a local group home training site.

→ **Interagency Linkages and Responsibilities:**

- ✓ Nina's special education will develop task analyses, identify tactual and signed prompts, and provide systematic instruction.
- ✓ Nina' case manager and parents will meet with an identified real estate agent to discuss availability of rental property in the desired neighborhood.
- ✓ Nina's case manager and parents will meet with a representative from the department of social services to explore use of a Medicaid waiver to provide support services.

- **Postsecondary Education Future Vision:**
  Joel will enroll in and complete a two-year animal care technician program at the local community college.

→ **Annual Goal:**

- ✓ Joel will demonstrate the entrance requirements for the local community college.

→ **Short-Term Objective:**

- ✓ Joel will complete a written application, an interview, and an orientation visit to the college campus with assistance from his guidance counselor and parents.
- ✓ Joel will increase his English reading and writing ability to an eighth grade level with daily instruction from his classroom teacher.
- ✓ Joel will enroll in a summer paid work experience at a local veterinarian's office with assistance from his vocational education teacher and rehabilitation counselor.

→ **Interagency Linkages and Responsibilities:**

- ✓ The rehabilitation counselor will meet with Joel and his parents to develop an IWRP including a plan for college tuition,transportation, adapted computer, and interpreter services.
- ✓ The O&M instructor will provide orientation and route training to Joel at the college campus.

- **Education Quality Indicators Checklist**
  Table 2.4, on the following pages, was designed by HKNC-TAC staff to guide educators in assessing the individualization and appropriateness of high school programming for a young adult who is deaf-blind. It may be used to assess and modify current high school programs, to design a new program for a new student, or to develop a technical assistance request plan with an appropriate provider.

TABLE 2.4

Helen Keller National Center - Technical Assistance Center (HKNC-TAC)

Education Quality Indicators Checklist

Student's Name: _____ Student's Date of Birth: _____ Telephone Number: ( ) _____

Name of Program: _____ Service Provider or Teacher's Name: _____

Type of Assessment: ( ) Initial ( ) Ongoing Date of Assessment: _____ (M/D/Y) Person Completing Assessment: _____

Quality Indicator	Assessment Method R = Review of Records O = Observation of Student I = Interview with Service Provider and/or Family S = Administration of standardized assessment F = Administration of functional or teacher-made assessment	Rating of Indicator 0 = Not applicable to student 1 = No evidence in student's program 2 = Little, uneven, and/or inconsistent evidence in student's program 3 = Substantial, even, and consistent evidence in student's program	Technical Assistance Need L = Low priority need M = Medium priority need H = High priority need
I. COMMUNICATION			
Expressive A. Review expressive communication modes at least annually including ASL/SEE, tactile sign, symbol or object boards, communicative behaviors and other communication modes	R O I S F	0 1 2 3	L M H
B. Review communicative intent of aberrant behaviors (if needed)	R O I S F	0 1 2 3	L M H
C. Evaluate out-of-school environments to identify communicative demands and teach alternative systems	R O I S F	0 1 2 3	L M H
D. Review current vocabulary and teach new vocabulary based on communicative demands of environments	R O I S F	0 1 2 3	L M H
E. Review and develop name signs or recognition symbols for new staff members and community members	R O I S F	0 1 2 3	L M H
Receptive F. Review receptive communication at least annually including ASL/SEE, tactile sign, symbol or object boards, communicative behaviors, and other communication modes	R O I S F	0 1 2 3	L M H
G. Evaluate out-of-school environments to identify communicative demands and teach alternative systems	R O I S F	0 1 2 3	L M H
H. Review current vocabulary and teach new vocabulary based on demands of environment	R O I S F	0 1 2 3	L M H

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I. Review communicative behaviors which indicate student understood the message given to him/her	R O I S F	0 1 2 3	L M H
J. Review latency period between what was communicated to student and student response	R O I S F	0 1 2 3	L M H

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Quality Indicator	Assessment Method R = Review of Records O = Observation of Student I = Interview with Service Provider and/or Family S = Administration of standardized assessment F = Administration of functional or teacher-made assessment	Rating of Indicator 0 = Not applicable to student 1 = No evidence in student's program 2 = Little, uneven, and/or inconsistent evidence in student's program 3 = Substantial, even, and consistent evidence in student's program	Technical Assistance Need L = Low priority need M = Medium priority need H = High priority need
F. COMMUNICATION (continued)			
K. Review other sources of sensory input to assist in receptive communication and student identification of location (e.g., smells in kitchen or bakery)	R O I S F	0 1 2 3	L M H
G. VISION			
A. Schedule medical exam annually if genetic condition, accompanying disabilities, surgical condition, or pathology exist (e.g., glaucoma, diabetic retinopathy, Usher syndrome)	R O I S F	0 1 2 3	L M H
B. Schedule optometrist evaluation and exam every three years to provide correction if condition is not progressive, is a genetic condition or pathology exists	R O I S F	0 1 2 3	L M H
C. Assess visual behaviors in various environments annually if genetic condition, accompanying disabilities, progressive loss or pathology exist to determine appropriate adaptations/modifications	R O I S F	0 1 2 3	L M H
D. If there are no pathologies, genetic conditions, progressive loss or accompanying disabilities, schedule evaluations on as needed basis	R O I S F	0 1 2 3	L M H
E. If student has a genetic condition or behaviors that suggest a vision loss (e.g., wider stance, bumping into obstacles in lower and upper fields, difficulty traveling at night) accompanied by a congenital hearing loss, schedule an ophthalmological evaluation	R O I S F	0 1 2 3	L M H
H. HEARING			
A. Schedule medical or audiological evaluation if pathology, progressive/fluctuating loss, predisposed genetic condition, surgical condition (e.g., cochlear implant), accompanying disabilities or history of chronic ear infections exist	R O I S F	0 1 2 3	L M H
B. Conduct hearing aid check at least annually to assess appropriate seal and functioning	R O I S F	0 1 2 3	L M H

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C. Conduct assistive listening device check at least annually to assess functioning	R O I S F	0 1 2 3	L M H
D. Assess hearing behaviors in environments annually if pathology, medical condition, surgical condition, progressive or fluctuating loss, or accompanying disabilities exist to determine appropriate modifications and adaptations	R O I S F	0 1 2 3	L M H

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III. HEARING (continued)			
E. Conduct evaluations in community, living, vocational, and post secondary environments	R O I S F	0 1 2 3	L M H
IV. ORIENTATION & MOBILITY			
A. Review need for travel in familiar and unfamiliar indoor/outdoor environments	R O I S F	0 1 2 3	L M H
B. Based on etiology, student preference, and family input, develop a plan for travel strategies (e.g., cane, sighted guide, protective techniques, trailing, landmark, and orientation within indoor/outdoor environments including night travel)	R O I S F	0 1 2 3	L M H
C. Familiarize student annually to different or same classrooms and environments	R O I S F	0 1 2 3	L M H
D. Conduct route planning annually in all environments identified by student, family and IEP team	R O I S F	0 1 2 3	L M H
E. Review community or mass transit travel skills and needs including bus schedules, use of TDD to access taxi, and acquisition of bus pass	R O I S F	0 1 2 3	L M H
F. Review emergency procedures at least annually	R O I S F	0 1 2 3	L M H
G. Evaluate behaviors that would indicate the need for travel skills and mobility devices (e.g., bumping into objects, wider gait pattern, missing stairs, etc.)	R O I S F	0 1 2 3	L M H
H. Evaluate skills and travel needs in expanded community environments	R O I S F	0 1 2 3	L M H
I. Evaluate route planning in both indoor/outdoor, familiar/unfamiliar environments including routes close to jobs and home for efficient and safe travel	R O I S F	0 1 2 3	L M H
J. Evaluate need to develop emergency assistance if needed during travel	R O I S F	0 1 2 3	L M H

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K. Evaluate need for inclement weather skills training	R O I S F	0 1 2 3	L M H
V. HEALTH/MEDICAL			
A. If individual has congenital rubella syndrome, assess possibility of additional manifestations of the syndrome (e.g., heart problems, neurological problems, growth problems, genitourinary problems)	R O I S F	0 1 2 3	L M H
V. HEALTH/MEDICAL (continued)			
B. Schedule medical and health evaluation and exam annually with medical/health care provider if a pre-existing condition, complex health care needs, chronic illness, or accompanying disability exist	R O I S F	0 1 2 3	L M H
C. Review health care plan and regimen annually with school personnel	R O I S F	0 1 2 3	L M H
D. Review side effects of medication annually	R O I S F	0 1 2 3	L M H
E. Evaluate behaviors to monitor change in medical status (e.g., rubbing/poking eyes may indicate glaucoma)	R O I S F	0 1 2 3	L M H
F. Review the student's settings annually with community emergency care providers and family	R O I S F	0 1 2 3	L M H
G. Provide annual training in CPR, First Aid, and Heimlich Maneuver for all school personnel involved with student	R O I S F	0 1 2 3	L M H
H. Review infection control plan at least annually	R O I S F	0 1 2 3	L M H
I. Review equipment for size, age, and functionality	R O I S F	0 1 2 3	L M H
J. If individual has congenital rubella syndrome, assess possibility of additional manifestations of the syndrome (e.g., diabetes, heart problems, thyroid, neurological problems, growth problems, genitourinary problems, panencephalitis)	R O I S F	0 1 2 3	L M H
VI. ENVIRONMENTS			

Quality Indicator	Assessment Method R = Review of Records O = Observation of Student I = Interview with Service Provider and/or Family S = Administration of standardized assessment F = Administration of functional or teacher-made assessment	Rating of Indicator 0 = Not applicable to student 1 = No evidence in student's program 2 = Little, uneven, and/or inconsistent evidence in student's program 3 = Substantial, even, and consistent evidence in student's program	Technical Assistance Need L = Low priority need M = Medium priority need H = High priority need
In-School			
A. Provide in-school vision itinerant services or consultation services (number of hours and type of service delivery determined by student need)	R O I S F	0 1 2 3	L M H
B. Ensure appropriate accommodations are in compliance with IDEA and ADA	R O I S F	0 1 2 3	L M H
C. If classes rotate or change, check adaptations or modifications annually in environments where student functions (e.g., illumination, size, distance, contrast, color, glare)	R O I S F	0 1 2 3	L M H
D. If classes do not rotate or change, check environmental adaptations/modifications if pathology, genetic condition, accompanying disabilities, or progressive vision loss exist (e.g., illumination, size, distance, contrast, color, glare)	R O I S F	0 1 2 3	L M H
Out-Of-School			
E. Ensure accommodations are in compliance with IDEA and ADA	R O I S F	0 1 2 3	L M H
VII. ACTIVITIES/SCHEDULES			
In-School			
A. Review schedule to ensure that activities have clear beginnings and endings	R O I S F	0 1 2 3	L M H
B. Review schedule to determine: (a) construction (e.g., object cues, braille); (b) portability; (c) environmental appropriateness; (d) number of schedules needed; and (e) appropriate communication symbols	R O I S F	0 1 2 3	L M H
C. Review in-school schedule to ensure natural, logically occurring sequences and routines throughout the day and routines which are typical of the age group	R O I S F	0 1 2 3	L M H
Out-Of-School			
A. Review schedule used at home and make adjustments as needed	R O I S F	0 1 2 3	L M H
B. Review activities conducted at home to ensure family's "normal" routines	R O I S F	0 1 2 3	L M H

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C. Review out-of-school activities based on student choice, family involvement and community presence (as determined by PFP or MAPS)	R O I S F	0 1 2 3	L M H
D. Review schedules to ensure that activities have clear beginnings and endings	R O I S F	0 1 2 3	L M H
E. Ensure accommodations are in compliance with IDEA and ADA	R O I S F	0 1 2 3	L M H
VIII. EDUCATION			
Academic A. Evaluate intervenor or interpreter services annually	R O I S F	0 1 2 3	L M H
B. Provide career exploration and career preparation activities	R O I S F	0 1 2 3	L M H
C. Review course content annually/ensure appropriate print/braille materials and technology (e.g., CCTV)	R O I S F	0 1 2 3	L M H
D. Begin videotape/data-based portfolio of vocational activities	R O I S F	0 1 2 3	L M H
E. Begin or review PFP or MAPS process for vocational/post-secondary goals	R O I S F	0 1 2 3	L M H
Academic (continued) F. Select course work based on student choice	R O I S F	0 1 2 3	L M H
G. Review extracurricular activities annually for school/community interests and inclusion	R O I S F	0 1 2 3	L M H
Functional H. Review life skill domains annually (i.e., community, vocational, rec/leisure, school) for activities which are based on parent input and student choice	R O I S F	0 1 2 3	L M H
I. Review technology used in classroom settings for adaptations/adjustments	R O I S F	0 1 2 3	L M H
J. Review extracurricular activities in school/community for interests and inclusion	R O I S F	0 1 2 3	L M H

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K. Begin videotape/data-based portfolio of vocational activities	R O I S F	0 1 2 3	L M H
L. Begin or review PFP or MAPS process for vocational goals	R O I S F	0 1 2 3	L M H
M. Evaluate intervenor or interpreter services annually	R O I S F	0 1 2 3	L M H
N. Develop annual statement of transition services as part of the IEP	R O I S F	0 1 2 3	L M H
IX. RELATIONSHIPS			
A. Begin or review relationships with non-disabled peers by conducting MAPS or PFP process	R O I S F	0 1 2 3	L M H
B. Evaluate plan for disability awareness in school for students with and without disabilities	R O I S F	0 1 2 3	L M H
C. Evaluate need for specific support groups for family and student (e.g., Usher support groups or AADB)	R O I S F	0 1 2 3	L M H
D. Evaluate plan for intervenors or interpreters to facilitate interactions with peers	R O I S F	0 1 2 3	L M H
E. Evaluate strategies for developing relationships and friendships with community members in community activities	R O I S F	0 1 2 3	L M H
F. Evaluate need for a peer mentor to assist in transition to new environments	R O I S F	0 1 2 3	L M H

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X. TRANSITION OF SUPPORT SERVICES			
A. Initiate contact with state vocational rehabilitation services (including general rehabilitation, services for the blind or services for the deaf depending on state agency responsibility) to determine eligibility needs	R O I S F	0 1 2 3	L M H
B. Review need for educational advocacy or self advocacy supports for parents and student	R O I S F	0 1 2 3	L M H
C. Review need for independent living services (with services for the blind or centers for independent living)	R O I S F	0 1 2 3	L M H
D. Evaluate need for counseling services for family and/or student	R O I S F	0 1 2 3	L M H
E. Review SSI eligibility/work incentives	R O I S F	0 1 2 3	L M H
F. Review need for home health services	R O I S F	0 1 2 3	L M H
G. Review need for respite services	R O I S F	0 1 2 3	L M H
H. Review need for family support groups	R O I S F	0 1 2 3	L M H
I. Review need for estate/guardianship planning	R O I S F	0 1 2 3	L M H
J. Review need for medical waiver services	R O I S F	0 1 2 3	L M H
K. Review need for transportation services (in- and out-of-school)	R O I S F	0 1 2 3	L M H
L. Review need for existing adaptations regarding college entrance examinations (e.g., ACT or SAT)	R O I S F	0 1 2 3	L M H
M. Review graduation requirements and high school diploma requirements	R O I S F	0 1 2 3	L M H
N. Review need for support services in post-secondary education environments (e.g., notetakers, interpreting, etc.)	R O I S F	0 1 2 3	L M H

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CHAPTER THREE

Communication Instruction and Supports for Transition-Age Youths Who Are Deaf-Blind

☞ *by deVergne Goodall*

What is Communication?

- Communication is an exchange of information between two or more people. People communicate to relay information, gather information, request a change in a person's behavior or to convey needs. Youths who are deaf-blind may experience difficulty in either expressive or receptive communication or more typically, in both areas.

What are the Functions of Communication?

- Function is the intent or purpose of communication. Communicative functions include requesting assistance, relaying information, seeking information, protesting, initiating, responding, and maintaining social interactions. Communication functions vary across environments, activities, and interactions.

What Forms of Communication are Used by People Who Are Deaf-Blind?

- **Deaf-blind youths typically use more than one form to communicate:**

→ Nonsymbolic Forms
- Vocalizations
- Body Movements
- Facial Expressions
- Gestures
- Behaviors
- Manipulation of a person or object
- Eye Gaze
- Touch

→ Symbolic Forms
- Pictures or Photographs
- Survival Signs/Home Signs
- Raised Alphabet Plates
- Sight Words/Touch Words
- Fingerspelling
- Print-On-Palm (POP)
- American Sign Language (ASL)
- Signed Exact English (SEE)
- Voice
- Speech Reading
- Reading/Writing
- Braille
- Telletouch
- Other Electronic Devices

What is Nonsymbolic Communication?

- Nonsymbolic communication is more informal, individualized, and nonconventional than symbolic communication. There are many common forms of nonsymbolic communication used by youths who are deaf-blind with multiple disabilities such as body movements, change in muscle tone, vocalizations, eye gaze, object manipulation, and gestures.

- Family members are often the first to assign meaning to specific nonsymbolic communicative intentions. For instance, Mary's father knows that when he presents her with a choice of orange juice or milk for breakfast, Mary will lean slightly forward in the direction of the desired beverage. Her sister knows that Mary will increase her vocalizations when she is enjoying an activity. With systematic and activity-based instruction, these communicative intentions can be reinforced and paired with symbolic forms, such as tactual signing or fingerspelling.

- Before symbolic communication systems can be learned, youths who are deaf-blind must understand the functions of communication. Their service providers and family members must also understand the youths' nonsymbolic forms and questions.

What is Symbolic Communication?

- Communication which is symbolic involves the use of rule-driven symbols, which are often highly abstract and complex, to communicate both receptively and expressively. Symbols can represent actions, objects or people. Symbolic systems of communication include the following forms: speech, ASL, SEE, Bliss symbols, line drawings, photographs or pictures, Rebus Pictures, written words, Braille, and oral language.

- Although most youths who are deaf-blind can become fluent in one or more forms of symbolic communication, many other transition-age youths who are deaf-blind with multiple disabilities do not effectively use symbolic systems and rely instead on non-symbolic communication. Thus, communication instruction and support needs vary tremendously across individuals.

What are Some Instructional Considerations in Teaching Communication as a Component of Transition Services?

- Touch or tactual cues are prompts involving touching a person or physically manipulating a person. They give the person who is deaf-blind information about what is going to happen or what has just happened. **Examples include:**

Form:	Function:
Parent or teacher makes an upward stroke on shoulder	**It is time to be moved from the wheelchair or bed**
Parent or teacher pushes an object away	**The activity is finished**
Parent or teacher presses firmly on shoulder	**Sit down**

- **Considerations when using touch or tactual cues include:**
  - ✓ Always inform the person who is deaf-blind what will happen next
  - ✓ Select no more than three or four cues for initial instruction
  - ✓ Professionals should use the same cues used by family members or caregivers
  - ✓ Family members or caregivers should always share their recognition of the youth's specific cues with professionals
  - ✓ Cues should be consistent across people, environments, and activities
  - ✓ Cues should be infused within all daily activities and interactions
  - ✓ Cues should maximize residual visual and hearing
  - ✓ Cues should be age-appropriate

- Object Cues may be real (an actual can of soda), miniature (a small cup), associated (a spoon to indicate lunch) or abstract (a tennis shoe to indicate that the person is going to the park). **Examples include:**

Form:	Function:
Car key	**A ride to work**
Cassette tape	**Time for a leisure activity**
Spoon	**Time to eat**

- **Considerations when using object cues:**
  - ✓ Select no more than three or four objects for initial instruction
  - ✓ Work with family members and caregivers to select appropriate activities and objects
  - ✓ Select objects which are concrete and immediately paired with a specific activity (e.g., selecting a cup and getting a cup of coffee)
  - ✓ Objects should be age-appropriate
  - ✓ Consider residual vision and hearing as well as motor abilities
  - ✓ How will the youth demonstrate understanding of the function of objects? (e.g., reach for preferred object, initiate activity, use "yes" or "no")
  - ✓ Use objects across people, environments, and activities
  - ✓ Use objects for activities which have a delay in time (e.g., individual holds a car key while walking outside to the car for a ride)
  - ✓ Move to miniature or more abstract objects and ultimately pair with signs as the youth understands objects that are distanced in time from the activity

- Gesture Cues should only be used after a complete assessment of the individual's residual vision. Gestures are a natural part of the communication repertoire of all individuals and should be utilized with youths with adequate vision. **Examples include:**

Form:	Function:
Parent or teacher gestures "up"	**Stand up**
Parent or teacher gestures "goodbye"	**Goodbye**
Parent or teacher points to an object	**Pay attention to the object**

- **Considerations when using gestures:**
  - ✓ Consider the amount and type of residual vision
  - ✓ Consider the youth's use of object and touch cues to communicate
  - ✓ Use gestures already in the youth's repertoire through other modes (e.g., stroke on arm in upward motion to indicate "up")
  - ✓ Select two or three gestural cues for initial instruction
  - ✓ Infuse gestures within regular activities and interactions
  - ✓ Encourage imitation of gestures
  - ✓ Gradually introduce signs

- **Considerations When Using Functional Signs:**
  - ✓ Teach iconic signs first (i.e., signs that are very similar to the represented object or action)
  - ✓ Teach signs that are formed on the body first before those signed in the air
  - ✓ Teach symmetrical signs first
  - ✓ Consider frequency of usage when selecting signs for instruction
  - ✓ Select two or three signs for initial instruction
  - ✓ Pair signs with tactual or touch prompts, object cues, and gestures
  - ✓ Encourage initiation
  - ✓ Infuse signs within regular activities and interactions

Do Challenging or Inappropriate Behaviors Have a Communicative Function?

- A person who sends a message expects that message to have some effect upon the behaviors of others. Very often, youths who are deaf-blind with multiple disabilities use a repertoire of *"socially inappropriate" or "aberrant behaviors"* to communicate wants and needs, likes or dislikes simply because they do not have a symbolic communication system. As a result, they may be labeled as having "behavior problems" rather than having their behaviors viewed as having communicative intent. For instance, a person who bangs his or her hand on the table may be attempting to indicate boredom, frustration, or the need for personal attention. Although the form of communication may be an effective way to elicit a response from staff or family members, it is almost always socially inappropriate.

- Assessment of the communicative intent of a behavior can be a challenge for family members and professionals. The behavior should be assessed with respect to environments, people, and activities. It may be helpful to also ask the following questions when attempting to assess the communicative functions of behaviors:

  1. What is the motivation for this behavior?
  2. What are the circumstances surrounding the behavior?
  3. How often does the behavior occur?
  4. When does the behavior stop?
  5. What is the payoff?
  6. How soon after eliciting the behavior does the person receive the payoff?

7. Would these behaviors be seen as inappropriate if the person were not deaf-blind?

- After assessing the behavior, new and appropriate communicative behaviors should be taught to replace the inappropriate communicative behaviors. For example, a vibrating microswitch connected to a buzzer can be used to signal for attention rather than beating on the table. The youth may be taught to sign "no." The youth may be taught to present a desired object to the teacher to represent desire for a leisure activity. Activities may also need to be changed from nonfunctional to functional, real life activities that make sense to the youth.

What is an Activity-Based Approach to Communication Instruction?

- An activity-based approach to teaching communication relies on infusing communication instruction within functional, chronologically age-appropriate naturally occurring activities. This approach eliminates teaching communication skills in isolation of environments, activities, and functions.

- Activities are best thought of as a set of skills. For instance, the activity of preparing a sandwich includes many skills. Very often we have insisted on teaching these skills in isolation (one youth gets the bread, another acquires the meat, another chops the lettuce, etc.). The result is the acquisition of splinter skills but, not the ability to perform an entire activity as independently as possible and with whatever modifications and strategies are necessary to assure success.

- When identifying functional activities for instruction with family members and youths it is important to define "functional." Functional simply means that if a youth does not learn to do this activity as independently as possible, someone would have to do it for him or her. Thus functional is highly individualized and dependent upon the future vision outlined in the IEP/transition plan.

- Communication instruction should be woven into naturally existing activities that occur every day. Opportunities to communicate with a variety of people, materials, and in different environments should be maximized. The instructor and youth who is deaf-blind must be considered communication partners.

- Environments can also be arranged to encourage communication. For instance, a crucial object which is part of a natural routine can be removed from the setting to encourage the individual to ask for it. Choices can be given (dressing, meals, snacks, leisure activities, etc.) and opportunities for the use of different forms and functions of communication should be emphasized.

TABLE 3.1

Rules of Thumb for Activity-Based Communication Instruction

- ✓ Position yourself at the same physical level, side-by-side with the youth
- ✓ Set the youth up for success
- ✓ Reinforce all appropriate communicative behaviors
- ✓ Never teach communication in isolation of activities and objects
- ✓ Infuse communication within all real life environments, activities, and interactions
- ✓ Give multiple opportunities for communication using a variety of forms and functions
- ✓ Use a variety of materials, people and environments
- ✓ Keep environments, activities, and interactions age-appropriate and functional
- ✓ Recognize the probable need for multiple forms in community settings
- ✓ Identify nonsymbolic communicative behaviors and assign meaning to them. Teach symbolic alternatives
- ✓ Pair touch and tactual cues, gestures, object cues and signs
- ✓ Recognize that everyone has a form of communication--the challenge is to discover it!

What Questions Should I Ask Before Developing a Communication Instruction Plan?

- ✓ What FORMS does the person use to communicate?
- ✓ What FUNCTIONS does communication serve for this person?
- ✓ Is the youth aware of the effect of his/her communication upon the receiver?
- ✓ How consistent are non-symbolic communicative behaviors?
- ✓ In what environments do these behaviors occur?

- ✓ How frequently do these behaviors occur?
- ✓ With whom does the person currently communicate and potentially need to communicate?
- ✓ What does the person enjoy communicating about?
- ✓ What are his/her favorite activities?
- ✓ Does the person initiate?

A communication system is the total package of communication forms, individualized to a youth's skills and support needs. A system may include one or more of the following: written note cards; braille alphabet card, object cues electronic devices, etc.

TABLE 3.2

Characteristics of Successful Communication Systems

- ✓ The system should be portable
- ✓ The system should be age-appropriate
- ✓ The system should be socially acceptable
- ✓ The system should be easily understood by the general public
- ✓ The system should be expandable
- ✓ The system should be effective across a variety of environments, activities, and interactions
- ✓ The system should be durable

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CHAPTER FOUR

Addressing the Medical and Health Issues of Transition-Age Youths who are Deaf-Blind[1]

M. A. Theresa Cuce and Jean Houghton

What are the Major Etiologies Associated with Deaf-Blindness Among Transition-Age Youths?

There are many causes of dual sensory impairment or deaf-blindness. Two of the most common causes among children and young adults are Usher syndrome and Congenital Rubella syndrome, but Regenbogen and Greear (1985) note that there are at least 80 syndromes associated with visual and auditory losses. In addition, prematurity, toxins, and trauma are also associated with deaf-blindness among children and young adults.

Usher syndrome is the combination of congenital hearing loss, ranging from mild to profound, and retinitis pigmentosa (RP), an eye disorder that involves night blindness, progressive loss of peripheral vision, and eventual variable loss of central vision (Duncan, Probst, Finkelstein, Vernon, & Hollingsworth, 1988). Although there is no medical treatment for Usher syndrome, genetic counseling can assist families in identifying their chances of having [illegible] children. [illegible]

[illegible] With the hearing loss associated with Usher syndrome is congenital, that is present from birth, the impairment may range in severity from mild to profound and may affect the individual from the lowest [illegible] (Duncan et al., 1988). Usher syndrome most commonly manifests itself in one of two distinct types, Type I or Type II, although more recent research indicates two additional, but less frequently occurring types, Type III and Type IV (S. Davenport, personal communication, August 3, 1993). Type I consists of profound congenital deafness, balance problems and the manifestation of RP usually in the late childhood or early teen years. Type II develops slower and is more progressive, with moderate to severe hearing loss, no balance problems and the onset of RP beginning around age twenty. The progression of the visual symptoms is quite slow: 50 to 70 percent of Usher syndrome patients maintain reading vision until the age of 40 to 50 (Duncan et al., 1988). About 90% of all persons with Usher syndrome have either Type I or Type II. (Boys Town National Research Hospital, undated).

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concerns as when responding to the needs of deaf-blind individuals and their families. Some basic questions to consider:

- Does the service provider have any prior experience with youths who are deaf-blind or have other service disabilities?
- Is the service provider willing to spend the extra time it may take to communicate with someone who is deaf-blind?
- Does the service provider have too large a caseload to ensure time to listen to concerns and to research new health and behaviors that may have a medical origin?

Prepare the Medical and Health Care Professional

Because most medical and health care professionals have not had experience with young adults who are deaf-blind, they may not even be familiar with the general characteristics and support needs of youths who are deaf-blind. To establish a positive relationship with the service provider even before he or she meets the new patient, it is helpful for educators and families to prepare the professional. When arranging an initial appointment, the following questions and concerns from all parties can be raised and discussed. Medical and health care professionals may ask some of these common questions.

- Communication
  - Will an interpreter be needed? Will written communication need to be used?
  - Will service providers, family members, or friends be needed to assist with communication?
- Cognitive abilities
  - How much information and terminology will the patient be able to understand?
  - Will service providers, family members, or friends be needed to assist with decision-making?
- Mobility
  - Will a guide dog, wheelchair, cane, or other assistive mobility devices be needed? Will sighted guide be needed?

→ **Past medical history -**

- ✓ What is the etiology of the dual sensory impairments?
- ✓ What was the age of onset?
- ✓ Have there been prior medical procedures?
- ✓ What are current medications?
- ✓ What is the specific reason for **this** office visit?

→ **Insurance -**

- ✓ What is the patient's current health insurance coverage?
- ✓ What procedural guidelines must be followed?

3. **Schedule the Appointment**

Because service providers' offices are often crowded, busy places, it is in everyone's best interest to try to schedule the appointment during the quietest times of the day, and the slowest days of the week or month. There are some general suggestions that service providers, and families may find helpful: first appointment of the day; the last appointment before the office closes before lunch or dinner; the first appointment after lunch or dinner; the last appointment of the day; or during holiday or mid-week. Regardless of what time an appointment is scheduled, it is a good practice to call an hour before the appointment to see if the service provider's appointments are running according to schedule.

4. **Obtain Medical Forms**

It is helpful to obtain and complete any pertinent office forms before the initial visit. Besides saving time, frequently the office requests information about family history or other aspects of the person's life of which the educator or patient may be unaware.

5. **Prepare the Patient**

In thinking about preparing a youth who is deaf-blind for a routine office visit, consider the type of service provider needed and the kind of examination to be performed as well as the sensory losses and associated disabilities of the patient. Use role play, object cues, and other methods of communication to prepare the youth. Appropriate dress should also be considered.

6. **Verify Medical History and Health Care Insurance**

Educators who escort deaf-blind patients to medical and health care appointments must be prepared to assist new medical and health care professionals in

understanding the patient's complete medical history, including etiology and age of onset of the sensory losses, current and past medications, known allergies, past medical procedures, and immunization history. Escorts may find it helpful to request copies of all records across multiple medical and health care professionals for maintenance in one personal file. Another important concern is medical insurance. Some physicians are not willing to accept all types of insurance, so this question should be asked in the service provider preparation interview or office visit. Before visiting the service provider, contact the individual insurance carrier to become familiar with their billing and service provision guidelines. Insurance companies can also be helpful in providing a list of participating service providers.

What are some of the Most Common Visual Impairments Associated with Deaf-Blindness?

- **Cataract** - Cataracts result in cloudiness (opacity) of the lens in the eye. This condition can cause hazy vision or decreased acuity. In brightly lighted areas, youths may be bothered by excessive glare, and in dimly lighted areas, youths may be bothered by darkness depending on the location of the cataract.

- **Diabetic Retinopathy** - Diabetic retinopathy causes hemorrhages, swelling, or scarring of the retina and is associated with long-term diabetes. Portions of the visual field may become hazy or opaque resulting in blind spots (scotomas). The individual may have difficulty tracking moving objects, and may have difficulty reading.

- **Glaucoma** - Glaucoma causes increased pressure in the fluid of the eye (aqueous humor). If left untreated, glaucoma can cause permanent damage to the optic nerve. Vision may diminish peripherally or create arc-shaped patterns depending on the type of glaucoma. Youths may complain of eye pain, fluctuating vision, or an increased sensitivity to glare.

- **Macular Degeneration** - Macular degeneration is deterioration of the macula (i.e., center portion of the retina). It is a progressive disorder causing the loss of central vision. Peripheral vision remains intact. Youths may experience a loss of detail in distance vision, and difficulty reading and writing.

- **Optic Atrophy** - Optic atrophy is degeneration of the optic nerve. This condition results in reduced visual acuity. Youths usually prefer materials held close to the eye and bright lights.

- **Retinal Detachment** - Retinal detachment is the separation of the light sensitive layer of the retina. This condition usually results in scotomas. Youths may have difficulty detecting objects that fall within the scotoma, and may have possible peripheral field loss depending on the location of the detachment.

- **Retinitis Pigmentosa** - Retinitis pigmentosa (RP) is a hereditary progressive degeneration of the retina resulting in loss of peripheral vision ("tunnel vision") and night blindness. Central acuity may or may not be affected. Youths most likely will have difficulty detecting objects or peripheral motion, and adjusting to changes in light. Regular print typically is preferred. Night travel often is difficult.

TABLE 4.1
Visual Acuities Classifications and Functions

VISUAL ACUITIES	CLASSIFICATION	FUNCTION
20/20 - 20/40	Normal Vision	Normal
20/40 - 20/70	Mild to Moderate Loss	Some difficulty seeing street signs although traffic lights are discernable.
20/70 - 20/200	Moderate Loss	May have difficulty seeing traffic lights or signs without a telescopic aid for driving (legally required). Telescopic help is needed for blackboard viewing, or the youth should be seated at least 5-6 feet, or closer to the blackboard.
20/200 - 20/600	Severe Loss	Unable to legally drive. Faces are blurred. The blackboard may not be discernable without a telescopic aid. Usually the youth will need to sit within 5 feet to see the television set. Legal blindness with correction.
20/600 or less	Extreme Loss	Central scotoma. Must eccentrically fixate in order to see faces. Very hazy. Unable to see detail.

20/200 generally is considered legal blindness.

Why are Updated, Current Vision Assessments Important for Transition-Age Youths?

→ Visual loss and support needs during the transition from adolescence to adulthood are challenging both to the youth and adult service providers.

→ Assessing and maximizing visual potential in transition-age youths is crucial in attaining employment, postsecondary education, community living, social, and recreational opportunities.

→ Maximizing residual vision allows youths to function more effectively and independently in a greater variety of community environments.

→ Changes in visual abilities have important implications for both communication and mobility across environments.

Who are the Professionals Associated With Visual Impairments?

→ **Ophthalmologist**
A physician (MD) who specializes in the diagnosis, medical, and surgical treatment of eye disorders.

→ **Optometrist**
A health care provider who performs diagnostic evaluations to determine, and treat medical and functional anomalies of the visual system. An optometrist may prescribe glasses, magnification, and other optical devices.

→ **Optician**
A technician who prepares eye glasses. In some states, an optician can dispense contact lenses.

→ **Low Vision Specialist**
A professional (sometimes an ophthalmologist or optometrist), who is specifically trained to evaluate individuals with non-medically curable eye problems. A low vision specialist may suggest specific low vision aids and strategies to address the educational, vocational, and independent living needs of individuals with visual impairments.

What Information Should a Vision Assessment Provide?

→ **Visual Acuities**

Visual acuities often are classic indicators of legal blindness (20/200 with correction). (See Table 4.1.)

→ **Visual Field Losses**

Visual field losses often are indicators of legal blindness. Most states use a 20 degree visual field or smaller as definition of legal blindness.

→ **Refractive Status**

Refractive status gives the service provider an idea of the youth's need for glasses in order to see as clearly as possible. Refractive status may change depending on the pathology, strength of the retina, or as a result of the aging process.

→ **Complete Diagnoses**

Complete diagnosis gives the service provider a prognosis for future visual changes, a classification of the vision loss, potential support needs, and appropriate instructional strategies for a period of time.

→ **Special Testing**

Special testing is used to define prognostic factors, determine diagnoses, and help decide on appropriate low vision aids for the youth. Commonly used testing procedures include electroretinography, visually evoked response (VER), threshold visual fields, and dilated fundus examination with fluorescein angiogram. For example, electroretinography can determine an Usher syndrome diagnosis early, allowing a more appropriate prognostic plan, and suggestions for appropriate modifications. Fluorescein angiography is most effective for youths with retinal vascular diseases, such as diabetic retinopathy.

→ **Auditory Trainers**

Auditory trainers have been successfully used to assess vision and low vision needs for youths with hearing losses. It is essential that the youths attend visual exams with a hearing aid that is operative. The auditory trainer is a device that allows amplification beyond that of a normal in ear hearing aid.

→ **Telescopic Aids and Field Expanders**

A report should include the function of the specific optical device, the designation of visual acuities, magnification power, as well as limitations of the device. Field expanders have minification as opposed to magnification.

Non-optical aids and electronic magnification aids also should be included in the report. For example, closed circuit television (CCTV) system evaluation should include the magnification range recommended for specific print sizes, whether normal or reverse contrast to be used, and the recommended color of the screen and/or unit.

What Does the Low Vision Evaluation Seek to Accomplish?

- The low vision evaluation is tailored specifically for the purpose of finding the most appropriate devices to aid the youth in vocational and education pursuits, appropriate modifications and adaptations, and visual strategies and techniques. For example, an evaluation for reading capabilities should include the size of readable print, the distance between the eye from the reading material, reading speed, and a description of supplemental lighting if needed.

Questions to Ask From a Visual Assessment

1. What is the cause of this youth's visual impairment?
2. Is any medical treatment required? Are any visual aids required?
3. Is the visual impairment likely to get worse, better, or stay the same?
4. Should educators attend to any particular behaviors (e.g., tearing, redness, eye poking, eye rubbing, etc.) that might signal the need for professional attention?
5. What (if any) restrictions should be placed on the youth's activities?
6. Should the youth wear glasses or NOIR lenses for indoor or outdoor travel? If so, what is the prescription and what degree of UV lenses should the individual wear?
7. Should the youth wear orange or yellow tinted lenses for travel, visually demanding work, or less visually demanding work to enhance contrast?
8. Were you able to determine accurate or gross visual acuity measures? If so or if not, does the individual appear to be grossly nearsighted or grossly farsighted? How does this affect the individual's ability to travel or see objects near or far?

9. Is the youth's focusing or eye muscle balance adequate? If not, please describe what viewing or scanning techniques should be used for the youth to see more clearly and effectively. Should objects be placed at a particular side for the youth to see more clearly?
10. Were you able to determine the field of vision? If so, were there areas of no vision in the field? Where? If portions of the visual field are absent, should the viewing field be magnified or reduced to see vision more efficiently?
11. If part of the visual field is missing, should the youth be instructed to use eccentric scanning or viewing techniques to obtain more visual information? Should objects or print be placed on a raised surface during work or leisure to obtain more visual information?
12. Will the youth be able to follow a moving object?
13. Will the youth work better with large print and objects, or small print and objects? At what distances?
14. What lighting conditions would be optimal for visual functioning? What wattage and type of light should be used? Where should the light source be placed (e.g., over the shoulder, to the side, etc.)?
15. Will the youth benefit from contrast?
16. Will the youth be effected by glare? If so, how should glare be reduced?
17. Will the youth be affected leaving brightly lighted indoor situations to dark or dark situations to brightly lighted situations? If so, what can be done to reduce the effect?
18. Should the youth use any optical aids to increase visual functioning (e.g., CCTV, magnification, telescope, cane travel etc.)?
19. Should the youth's vision ability fluctuate due to the nature of the condition or medication? If so, how will this effect the youth's work performance or activities of daily living?
20. When should the youth be examined again?

(Adapted from: Roberts, S., Helmstetter, E., Guess, D., Murphy-Herd, M.C., & Mulligan, M. (1984). Programming for students who are deaf-blind. Lawrence, KS: University of Kansas.)

What are Some of the Most Important Considerations About Hearing Losses and Deaf-Blindness?

- **There are three specific types of hearing loss: conductive, sensorineural and central.**

→ **Conductive -** A conductive hearing loss occurs whenever a barrier to sound is present in the outer or middle ear (Martin, 1991). Usually the quality of sound is good, however, the intensity is reduced. Many times the cause of a conductive hearing loss can be medically treated. There are many causes of conductive hearing loss: for example, excessive wax; outer or middle ear infection; a hole in the eardrum; genetic malformation of the outer and/or middle ear; and head trauma.

→ **Sensorineural** - Sensorineural hearing loss occurs when the inner ear or auditory nerve is damaged. The quality as well as the intensity of sound may be affected. People with sensorineural hearing loss often say that they hear but cannot understand the words. Usually, there is no medical treatment for this type of hearing loss, however, hearing aids can be utilized in most cases. There are many causes of sensorineural hearing loss: for example, excessive noise; certain drugs such as aspirin, cisplatin, streptomycin, kanamycin, tobramycin, etc.; genetic syndromes such as Usher, Hallgrens, etc.; maternal rubella; mumps; aging; and tumors.

→ **Central** - A central hearing loss occurs when damage to the brain precludes proper processing of auditory stimuli. It is important to remember that the final processing for hearing occurs in the brain. Therefore, it is possible to have a normal ear but still be "hearing impaired" because of a central processing disorder. It is also possible to have any combination of the three hearing losses at the same time.

▸ Along with classification by type, hearing loss is also classified by degree. Individuals may have a mild, moderate, severe, or profound hearing loss. The purpose of an audiological evaluation is to determine if an individual has a hearing loss, and if so, in what part of the ear the problem exists. An audiologist is an individual with at least a Master's degree who is trained in completing and interpreting evaluation of hearing. In most cases the audiologist works with a medical doctor in helping to diagnose a hearing loss. If it is determined that medical treatment is not indicated, the audiologist may be called upon to determine if amplification or other forms of auditory habilitation or rehabilitation are needed. The audiologist will test each ear using sounds (pure tones) of different pitches, as well as test the ability to hear and understand spoken speech (if the client uses spoken language). If the client is unable, due to cognitive or behavioral

constraints, to respond to the standard test procedure (for example, hand raising) a modified approach will be employed (example: a piece to a puzzle each time a sound is heard). For youths who are unable to complete the modified evaluation, behavioral observation can be employed. Certain behavioral responses like eye shift or vocalization, may be exhibited when a sound is heard. If none of these procedures are successful a physiological measurement of hearing can be administered: Auditory Brain Stem Response (ABR) audiometry. This is a technique that looks at changes of electrical energy in the brain stem when sound is present. The average test usually does not last for more than one hour. **The audiologist may ask for the following information:**

- ✓ Is there a family history of hearing loss?
- ✓ Which ear has better hearing?
- ✓ What is the history of childhood infections?
- ✓ Any history of ear infections?
- ✓ Current and/or past health problems?
- ✓ Which medications are used?
- ✓ Any history of noise exposure or head trauma?
- ✓ What are the results of past hearing evaluations?
- ✓ When did the problem begin and is it progressive?

TABLE 4.2

WHAT ARE THE RANGES OF HEARING LOSS?

LEVEL OF LOSS	DESCRIPTION	EFFECT	HEARING AID NEED
25 to 40 dB HL	Mild	Difficulty understanding normal speech	Needed in specific situations
41 50 55 dB HL	Moderate	Difficulty understanding loud speech	Frequent need
56 to 80 dB HL	Severe	Can understand amplified speech only	Needed for all communication
81 dB or more HL	Profound	Difficulty understanding amplified speech	May need supplemental speech-reading, aural rehab, or sign language

Questions To Ask From An Audiological Assessment

1. Does this youth use residual hearing for speech discrimination or environmental awareness?
2. How will background noise affect the youth's ability to utilize residual hearing?
3. How can the environment be altered to control background noise?
4. Is one ear better than the other?
5. How long will batteries last in the particular hearing aid used? Who can change them? What size are they? Where can they be purchased?
6. Who should be contacted if aids/devices need repair? Will a loaner be available?
7. What type of audiological stimulation (e.g., environmental sounds or speech sounds) are appropriate for the individual youth?
8. Can the audiologist do periodic in-services for staff regarding effects of loss, and/or maintenance of aids/devices?
9. For a youth who may be difficult to test, what exercises can be done to get the youth ready?
10. For youths who are using residual hearing for the purpose of communication, what are some strategies that can be used (e.g., speak louder, slower, etc.) for the individual youth?

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CHAPTER FIVE

Orientation and Mobility for Youths Who Are Deaf-Blind

☞ *by Joan Houghton*

What is Orientation and Mobility?

- An individual's ability to travel is comprised of two components, orientation and mobility. Orientation is described as an individual's ability to: (a) determine position in relationship to objects in an environment (Gothelf, Rikhye, & Silberman, 1988); (b) use remaining senses to establish position in space (Hill & Ponder, 1976); and (c) construct a mental map of the environment (Chapman & Stone, 1988). Mobility is described as the: (a) capacity for independent or assisted movement (Gothelf et al., 1988); (b) ability to move safely from one area to another (Chapman & Stone, 1988); and (c) purposeful movement from a fixed to a desired location within the environment (Cioffi, 1995).

- Traditional orientation and mobility (O&M) instruction according to Gothelf et al. (1988) was based on three principles: (1) where the youth is in the environment; (2) where the youth wants to go; and (3) what method is used to reach the destination. Joffee and Rikhye (1991) expanded the traditional model for youths with multiple disabilities to include: (4) how to recognize and initiate movement to a destination; and (5) when to terminate travel after the destination is reached.

- Currently, the focus of instruction for youths with dual sensory and multiple disabilities is based on a functional application of skills during natural opportunities within youths' daily routines. The infusion of skills training during the performance of typical activities and routines also has been recommended for orientation and mobility (Gee, Harrell, & Rosenberg, 1987). This rationale is founded on learning style characteristics of individuals with multiple and dual sensory impairments (Bailey & Head, in press). Selection of appropriate learning experiences is determined by the "criterion of ultimate functioning". This means skills are taught when they are needed in non-simulated settings where youths live, work, and play (Brown, Branston, Hamre-Nietupski, Pumpian, Certo, & Gruenwald, 1979). Partial participation is not determined by the mastery of prerequisite skills or independent performance of a skill sequence. The extent of youth's participation in chronologically age-appropriate, preferential, meaningful, and integrated activities is supported to the degree necessary to ensure instruction is meaningful to the

youth (Baumgart, Brown, Pumpian, Nisbet, Ford, Sweet, Messina, & Schroeder, 1982; Brown et al., 1979; Ferguson & Baumgart, 1991).

- The ultimate goal of O&M instruction is to enhance access to typical environments and increase opportunities for participation in everyday activities through the application of adapted travel methods that ensure safe, efficient, and effective travel. The youth is encouraged to function as independently as possible, within functional, meaningful, and natural settings (B. Bailey, personal communication, February 26, 1993).

What Considerations Need to be Made Regarding a Youth's Vision and Hearing Losses Prior to Transition to Adult Environments?

- It is important to identify the extent and onset of the youth's vision and hearing losses before transition, instruction, or adaptations in community environments are determined. The majority of youths who are deaf-blind are not totally deaf or totally blind (i.e., completely without sight and hearing) (Cioffi, 1995; Konar & Rice, 1984; Lolli, 1987). Lolli (1987) addressed various categories of congenital and adventitious vision and hearing losses that may influence orientation and mobility needs and goals for the youth including; a) congenitally blind and adventitiously deaf, b) congenitally deaf and adventitiously blind, c) adventitiously deaf and blind, or d) congenitally deaf and blind. Cioffi (1995) listed other considerations that are important to assess regarding the youth's vision and hearing losses, such as whether the extent of the vision and hearing losses are; a) partial or total, b) stable or progressive, and c) congenital or adventitious, as well as any accompanying disabilities that may interfere with independent travel. Houghton (1992) reported additional considerations of whether the; a) vision loss is central or peripheral, b) hearing loss is sensorineural, conductive, or mixed, c) vision and/or hearing losses fluctuate due to the nature of the syndrome or disease, or influenced by medication and medical intervention, and d) at-risk for vision or hearing losses (e.g., detached retinas and scarring of the tympanic membrane). For example, a youth who is in the early stages of Usher syndrome (i.e., congenital deafness with progressive peripheral vision loss due to Retinitis Pigmentosa) may be able to travel independently during day time hours or under sunny conditions (possibly with orange or yellow tinted shades to enhance contrast), but not at night or under cloudy conditions. Awareness of these variables becomes more useful and meaningful when assessment can include evaluation in environments frequented by the youth. The performance criteria remains the most legitimate method of

determining the effect of a disability (i.e., extent of the handicap) on an individual's ability to compensate, adjust, and adapt (i.e., function) to real life demands (Bailey & Head, in press).

- As with any type of education program based on performance in the community environments to which a youth is being transitioned, ecological inventories and discrepancy analyses of skills are conducted prior to instruction. Furthermore, a physical analysis of the environment (both indoors and outdoors) should be conducted to determine; a) visual and auditory requirements and needed adaptations, and b) salient features within the environment that the youth would use to organize and plan travel (including tactual, visual, and auditory features, landmarks, and clues).

- Indoor lighting (e.g., type, amount, intensity, and location), contrast (e.g., color and figure-ground), glare producing surfaces (e.g., unshaded windows and high gloss paint), size of print and objects in relation to body position, and color (e.g., tints, shades, and hues) should be evaluated to determine the impact on a youth's performance for travel and work within the environment.

- Outdoor lighting conditions, such as shaded areas, building overhangs, contrast between various travel surfaces (e.g., concrete from asphalt; grass from a sidewalk), glare (from snow or rain), and figure-ground will most likely affect a youth's travel (Jose, 1983; Morse & Lessard, 1975; G. Zimmerman, personal communication, October, 1992).

- Some indoor auditory conditions that need to be evaluated are amplification of sound for general announcements over public address systems, acoustics (e.g., noisy in a factory; quiet in a library), floor surfaces (e.g., carpet absorbs sound; tile reflects sound), echoes (e.g., gymnasium or automobile garage), and wall surfaces (e.g., auditory panels conduct and direct sound; concrete reflects sound in every direction). Outdoor auditory conditions that should be evaluated include traffic patterns and noise levels during scheduled times of the day (e.g., large and small vehicle traffic sounds paired with pedestrian voices during rush hours), ambient noises (e.g., continuous sound of an air conditioner or generator), and building positions in relation to the travel surfaces (e.g., a crowded continuous line of four story buildings within a short distance from the sidewalk or street may distort sound, or wide open spaces along travel routes) (Morse & Lessard, 1975).

- Visual, auditory, and tactual analyses also are important to conduct (e.g., wheelchair ramps at curbs or switching travel from carpeted to tiled surfaces). These conditions can

either interfere or enhance the youth's independent travel. Adjustments and adaptations are determined partially by the impact these conditions have on a youth's performance. For example, a youth may be instructed to turn off her hearing aid in order to cross a busy, noisy intersection. The noise created by the traffic and the position of the buildings in relation to the intersection may distort auditory information usually used to cross the street. Instead, the youth is instructed to utilize her vision by eccentric viewing techniques to determine when it is safe to cross. For another youth, the only safe method to cross the same intersection may be to avoid it. This youth is instructed to travel one block further to receive assistance from a crossing guard during rush hours.

What Type of O&M Instruction will a Youth who is Deaf-Blind Need in Community-Based Education Programs and in Adult Environments?

- O&M techniques, systems, and adaptations useful to youths who are deaf-blind in work, home, and community environments can vary as much as receptive and expressive communication modes needed by youths to interact with community members, family members, teachers, and friends. No one method or strategy is appropriate for every youth or for use in every environment. The application of travel skills and techniques largely depends on a combination of factors that include the context of an activity, environmental conditions, the youth's learning style and preferences, the youth's level of confidence, and the nature and degree of the youth's vision and hearing losses (e.g., congenital or adventitious; partial or total) based on the results of an O&M assessment.

- Konar and Rice (1984) identified categories of individuals who are deaf-blind by characteristics and suggestions for orientation and mobility assessment and training. For example, a youth who is congenitally deaf and adventitiously blind may need instruction which emphasizes sighted guide, diagonal cane techniques, and near and distance low vision aids (that enhance visual capabilities) to shop in mall areas both alone and with family members. A youth who is congenitally deaf and blind may need instruction which emphasizes orientation to home and work environments, a variety of long cane techniques for travel in environments that include changing conditions (e.g., co-workers leave file drawers and doors open or ajar), and protective techniques.

- For the majority of youths who are deaf-blind, mobility (assessment and instruction) should be conducted during the typical travel opportunities that are present in natural

occurring daily routines in actual environments. That is, assessment and instruction occur where the youth will be working, residing, or recreating after graduation from school (Bailey & Head, in press; Gee et al., 1987; Geruschat, 1980). It also is possible that some youths who are deaf-blind may acquire travel skills in simulated environments, then apply these skills to novel settings that very closely resemble environments where the youth will ultimately function. However, this depends on youths' individual learning styles and overall travel experiences (Horner, McDonnell, & Bellamy, 1986; Primrose, 1980).

- Based on the youth's current level of performance as determined by results of the assessment activities, skills are targeted for instruction and physical adaptations are identified for the youth to function as independently as possible. Training of expressive and receptive communication skills, orientation and mobility skills, visual and auditory skills, and fine and gross motor skills are embedded in actual activities. Specific instructional, transition related goals and objectives are determined by representatives of the youth's collaborative educational team (Bailey & Head, in press; Brown et al., 1979; Gee et al., 1987). These goals and objectives are outcome-based descriptions of what the orientation and mobility specialist, parents, vocational rehabilitation counselor, a representative from the Department of Vision Services and/or Hearing and Deafness, speech-language pathologist, vision specialist, educator, physical therapist, youth, and administrator believe can be accomplished in a one year period. For example, given familiarization to the work area including protective techniques, and receives instruction on effective receptive and expressive communication modes (e.g., receptively-print on palm; expressively-pre-printed communication cards or large print with felt markers on buff or yellow paper), the youth needs to function at half the required output with no more than two spot checks from a co-worker for a two hour work day including a 10 minute break. Route travel by sighted guide will be provided for areas where stairs and drop-offs are located, after which constant contact cane technique will be utilized independently for remaining familiar, flat surfaces.

- Actual work areas will be supplemented with an incandescent light source positioned over the youth's left shoulder for detail work accompanied by a stand magnifier. Breaks will need to occur over a periodic basis to reduce eye fatigue. An auditory trainer will be used by the youth's supervisor and the youth to receive job related instructions. Co-workers will use large print with black felt tip markers on buff or yellow paper to communicate with the youth, or print-on-palm.

- Outdoor travel adaptations will include the use of a sun visor to reduce direct illumination. Alternative routes will be designed to avoid crossing streets at dangerous intersections. Instruction on touch and constant contact techniques will be provided on a daily basis for the first two weeks when travelling to work. Time and distance measures will be implemented where outdoor landmarks are prominent. Outdoor route landmarks will consist of a mail box and newspaper stand. Clues consisting of low retaining walls and three poles prior to the entrance of the building. These landmarks and clues act as orientation markers for the youth to use when planning travel. Indoor landmarks and clues will consist of a water fountain immediately inside the front door and the metal door of the break room. The youth may choose to seek sighted guide assistance from an employee in the break room or travel to the workroom using constant contact technique.

What is the Role of an O&M Specialist for a Youth Who is Deaf-Blind Before Graduation and After Graduation?

- The traditional role of an O&M instructor is to teach safe, effective, and efficient travel strategies to individuals capable of generalizing those skills to novel travel situations (Bailey & Head, in press). Cioffi (1995) defined an O&M instructor's role to include assessment and instruction for individuals who are deaf-blind in safe and independent travel skills through the use of sensory information and tactual technique to "..open as many doors as possible to community access and participation" (p. 8). Bailey and Head (in press), Cioffi (1995), and Joffee and Cuff (1991) stressed the importance of an O&M instructor's involvement in transdisciplinary and interagency teams whose members develop and implement the youth's individual education plan and transition goals [to begin no later than 16 years of age and if appropriate, 14 years of age (IDEA, PL 101-476, 1990)].

- For those individuals who have graduated from public school programs, Von Schneden (unknown) indicated that O&M instructors have the same mobility goals (cf., Bailey and Head, in press; Cioffi, 1995) for youths currently enrolled in public school programs. Post-graduate youths usually receive O&M instruction through adult service agencies, such as Department of Vocational Rehabilitation (DVR), Department of Deafness and Hearing, or Commission for the Blind in many states. Often, these state agencies may further contract with other private agencies or private O&M contractors to extend this

service. Some of the contracted agencies may include Lighthouse for the Blind (P. Sinclair, personal communication, February 19, 1993), Societies for the Blind (G. Savel, personal communication, February 16, 1993), or through individual private contractors (B. Bailey, personal communication, February 26, 1993). These services typically are provided free of charge to the individual; however, there are some situations where an individual may not qualify for O&M services through DVR and have to assume the cost of instruction. Unlike youths whose instruction is determined by educational teams, the length and amount of O&M services for youths after graduation tends to be left to the judgement of the O&M instructor. These post-graduate youths receive instruction in immediate environments where they live, work, and access community businesses (e.g. grocery store, post office, or bank) (G. Zimmerman, personal communication, March 3, 1993). Additional responsibilities for the O&M instructor relative to post-graduate youths may include identifying and securing any needed adaptations and environmental modifications, or the eliminating hazards necessary to allow youths access to job or home settings (Von Schnaden, unknown). Transportation accommodations and accessibility issues protected by the American Disabilities Act (ADA, PL 101-336) also should be examined (ADA, 1990; Joffee, 1992a).

- The shortage of qualified vision personnel is a problem that has long been recognized in the literature (Bailey & Head, in press; Cioffi, 1995; Stewart & Zimmerman, 1990). Bailey and Head (in press) suggested the development or workable models for the provision of O&M services through transdisciplinary teaming and role release that has been successful in other related service areas, such as physical therapy and speech-language pathology. Role release allows members of the youth's educational team to exchange information and assume predetermined responsibilities related to each team member's primary position (Lyon & Lyon, 1980). For example, the speech-language pathologist provides the O&M instructor information on the use of tactual and printed communication cards for a youth to make a purchase at a convenience store. The O&M instructor then assists the youth in using the adaptation during communicative interactions with the clerk behind the counter. Likewise, the O&M instructor informs the speech-language pathologist and vocational teacher how the youth should position his cane while trailing to reach the break room. During break, the speech-language pathologist facilitates trailing skills by cuing the youth to place his hand in the proper position and monitoring the position of the cane in front of the youth's body.

- Cioffi (1995) and Tomaselli (1992) supported the principle of "role release" by suggestions related to travel instructions and training for non-certified O&M instructors. This release of roles may involve key individuals within the youth's life, such as family members, friends, supervisors, or Orientation and Mobility Assistants (OMAs) (Tomaselli, 1992). Furthermore, Cioffi (1995) cautioned that non-certified persons should assist in the demonstration and practice of agreed upon preliminary travel and safety skills. These skills may include self-protective skills, trailing, and sighted guide techniques to the youth.

- Orientation and mobility assistants (OMAs) increase the number of personnel available to support and assist in mobility training. They have provided some relief to the field through the provision of mobility instruction for both youths facing transition and post-graduate youths who otherwise would be placed on waiting lists due to the large demand (Tomaselli, 1992; Wiener & Uslan, 1990). Tomaselli (1992) emphasized the importance of OMA's to receive comprehensive training and instruction regarding job performance responsibilities. Their primary purpose is to reinforce previously taught skills, and provide additional practice time needed for skill maintenance within indoor travel (e.g., self-protective techniques or room familiarization). Committee members from Division IX of the Association for Education of and Rehabilitation of the Blind and Visually Impaired (AER) developed guidelines for the instruction, certification, and use of OMAs (Wiener, & Uslan, 1990). These guidelines clearly delineate the primary roles of supervision, monitoring, and reinforcement of instructional objectives developed by a certified O&M instructor. At no time is an OMA to assess initial skill levels, develop or change instructional plans, or introduce a new skill area (e.g., introduction of three point touch cane technique) (Tomaselli, 1992).

How does the Youth who is Deaf-Blind Access Public Transportation for Travel to and from a Job Site or Other Community Environments?

- Joffee (1992a) identified areas covered by ADA (1990) specifically for individuals with visual impairments and McCrone (1990) identified areas covered by ADA specifically for individuals with hearing impairments. Those areas included in ADA (1990) clearly written for individuals with visual impairments involve those issues of accessibility and accommodations for public transportation. For example, adjustments for protruding objects, detectable curb ramps, elevators with visible and audible signals, signage (e.g.,

height and width of letters), automated teller machines, and detectible warnings for wading pools and walking areas that intersect with vehicular traffic (Joffee 1992a). McCrone (1990) identified the following areas that are clearly delineated for individuals with hearing impairments in places of employment (e.g., provisions of interpreters, telephones compatible with hearing aids, or amplification systems), transportation services (and paratransit), public accommodations operated by private businesses (e.g., accessing telecommunications relay services or closed captioning), and telecommunications [e.g., telecommunications device for the deaf (TDD)].

- Accommodations specific to public transportation of individuals with both hearing and visual impairments include; a) illumination of bus route identification signage, b) lighting at bus doors and steps, c) priority seating assignments, d) vehicle destination and route signs, e) informational and directional indicators, f) signs on boarding areas, platforms and mezzanines for rail facilities, g) fare machines and gates, h) detectable warnings, i) escalators, j) coordination of platform and vehicle floor heights, and k) circulation path in mass transit facilities, clocks, and announcement of stops (Joffee, 1992b). Full compliance with ADA (1990) will occur over the next seven years for employers, public transportation authorities, and businesses.

- A youth who is deaf-blind prior to graduation should receive instruction on accessing public transportation systems (e.g., buses and taxis) if team members identify this as a goal on the youth's IEP. It is often an important part of successful transition since many youths need to be able to utilize public transportation in order to travel to and from work or attend community functions. After graduation, individuals may need to receive additional training if they change jobs or move to different locations. The O&M instructor can play an important role assisting both groups to access public transit systems within the context of real environments.

- Michaud (1987) identified two primary issues for a youth who is deaf-blind who wishes to use mass transit systems. These issues are expressive and receptive communication and alternative methods of sensory input. It can be an appropriate part of a youth's education for an O&M instructor to assist the youth in learning to acquire information regarding the schedule of public transportation, as well as teaching skills necessary to access public transportation.

- The youth needs to know how to gather preliminary information regarding the destination, location of the bus stop, transfers, times of departure and arrival, and cost of the trip.

This may be accomplished by accessing a hearing relay service and requesting a bus or train schedule in large print, or utilizing a TDD accompanied by a large print screen or braille output. The youth will most likely receive instruction on the most effective communicative mode necessary to interact with the bus driver. For example, the bus driver knows to stop in front of the youth who has her cane extended across her body. The youth is prompted by the O&M instructor to utilize ascending stairs technique before displaying communication cards to the bus driver which indicate the youth's destination. The youth feels a staple in the corner which cues her to display the card in the proper position for the bus driver to read (J. Cioffi, personal communication, March 4, 1993). The card contains written words, "Does this bus go to Fifth and Aiken? Tap my hand twice for yes and once for no" (D. Saurerburger, personal communication, November, 1992). The bus driver complies and taps the youth's hand two times. The youth displays a second card that indicates, "Will you tell me when the bus stops at Fifth and Aiken? Tap my hand two times for yes and once for no." Even though the driver may tap "yes," the youth may want to present this card to a passenger sitting next to her to serve as a back-up system for the driver. Another communicative method the youth may use to interact with the driver is print on palm (POP). Instructions on the communication card may inform the driver how to "write" in the youth's hand. After the youth exits at the bus, the O&M instructor would remind the youth to locate a series of pre-determined landmarks and clues (e.g., newspaper stand and mailbox, and the smell of the bakery) necessary to maintain orientation and determine the line of travel to the youth's destination.

TABLE 5.1
Mobility Assessment Questionnaire for Use By Educators

☞ *(developed by Joe Cioffi, HKNC, 1993)*

Name of Individual Being Assessed: _____

Name of Individual Conducting Assessment: _____

Date of Assessment: _____

Recommended questions: (to be filled out by a service provider or family member who is familiar with the Individual)

1. Do you walk independently from room to room in your home/school, or only in certain parts of your home/school? Are you comfortable as you walk?

2. Would you like to have assistance walking, or do you prefer to walk alone? Are there any situations where you feel you would like to have assistance?

3. Do you depend more on your residual vision, hearing, or tactual cues as you walk?

4. Are walls touched or followed visually as you walk in familiar areas of the home/school?

5. When you are walking in "unfamiliar areas," are walls touched or are they followed visually?

6. Do you have a visual memory of the home/school, and does this help you as you walk?

7. Are you able to travel as well in new areas, where you don't have a visual memory of landmarks, as you are in old familiar areas?

8. Do you ever bump, trip, or have any accidents as you walk at home/school/outdoors? If yes, where?

9. Do you have any problems walking on stairs? Is it difficult to find the first step or last step?

10. Do you have any problem finding curbs, potholes, or obstacles on the sidewalk? (If there is a concern about stairs or curbs, recommend that the youth avoid stairs and use the elevator.)

11. Do you need some time to adjust to the lighting change when you walk from outdoors to indoors? does glare from the sun make it difficult for you to see the sidewalk in from of you? Do you have sunglasses?

12. Do you have any problems walking in areas that are crowded or have poor lighting, e.g., cafeteria, lobby, auditorium, etc.?

13. Do you cross streets along? How?

14. What methods do you use to best communicate expressively and receptively? If you were to become lost or have a problem on the street, how would you get help from the public in an emergency?

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CHAPTER SIX

Developing Employment Opportunities For Youths Who Are Deaf-Blind

☞ *by Janet Steveley, Susan Killam, and Jane Everson*

WHAT IS THE PURPOSE OF VOCATIONAL ASSESSMENTS?

- Assessments in vocational training and job placement programs have historically attempted to provide information in three areas: program or service eligibility; employability, especially for rehabilitation services; and job development and job matching assistance.

- Two events have significantly changed the way professionals view vocational assessments. First, the emergence of supported employment as a "zero exclusion" and "place and train" employment model; and second, the reauthorization of the Rehabilitation Act of 1992 which emphases employment goals and supports instead of eligibility determination.

- The purpose of vocational assessments should be to collect *functional* information about an individual's wants and needs. The data collected during the vocational assessment process should yield a functional vocational profile of the deaf-blind youth and answer these questions:

  - ✓ What type of job interests the youth?
  - ✓ What skills does the individual have to perform this type of job? What additional skill training is needed?
  - ✓ What type of supports does the youth need and want -- for example, communication supports, environmental modifications, orientation and mobility supports, assistive technology, compensatory strategies?
  - ✓ How much support will the youth need -- time-limited, extended, natural, etc.?

WHY SHOULD FUNCTIONAL VOCATIONAL ASSESSMENTS BE CONDUCTED?

- Functional vocational assessments should be conducted by high school programs (special or vocational education) in collaboration with adult service programs (general rehabilitation, services for the blind, employment placement programs).

- Many youths who are deaf-blind have not received community-based vocational training as part of their high school education programs. Other youths may have experienced recent changes in their vision or hearing, and changes in their communication or mobility skills. Community-based situational assessments are one mechanism that may be used to observe and assess youths who are deaf-blind in a variety of community work environments. Information obtained from situational assessments enables transition planning team members to respond to many questions included in a vocational profile:

  - ✓ What are the youth's instructional needs -- types of prompts, type and schedule of reinforcement, performance differences across environments?
  - ✓ What are the youth's environmental adaptations/modifications needs -- sound enhancing, sound-dampening, near vision, far vision, color perception, depth perception, peripheral vision, glare-reduction, contrast discrimination?
  - ✓ What are the youth's communication skills and support needs -- with co-workers, supervisors, job coaches, community members?
  - ✓ What is the youth's physical endurance/stamina?
  - ✓ What are the youth's orientation and mobility skills? transportation needs?
  - ✓ What is the youth's job preference? ideal work schedule? ideal work location?

- Vocational profiles should be compiled following a review of current medical, visual, audiological, educational, psychological, communication, mobility, and vocational assessment records. They should also include information obtained during interviews with the youth who is deaf-blind, family members, direct service providers, and other individuals who know the youth well.

WHAT ARE THE STEPS IN CONDUCTING COMMUNITY-BASED SITUATIONAL ASSESSMENTS?

- **Step #1: Analyze Local Labor Market Information**
  - ✓ Analyze community labor market information to determine a variety of available jobs appropriate for individuals with dual sensory impairment
  - ✓ Identify positions that respond to the educational experiences and preferences of youths

- **Step #2: Determine a Variety of Positions**
  - ✓ Using information from the labor market analysis, identify major clusters of job types (e.g., clerical, food service, maintenance, library, computers, etc.)

- **Step #3: Identify Specific Employers**
  - ✓ Select specific businesses with the targeted positions
  - ✓ Consider developing several sites with one employer, such as at hotels, hospitals, universities, etc.

- **Step #4: Schedule and Conduct Analyses**
  - ✓ Contact the Personnel Director, Director, or Manager and explain the purpose and process of assessments
  - ✓ Schedule initial visits to describe program, tour worksite, and confirm adherence to U.S. Department of Labor guidelines
  - ✓ At initial or follow-up visit, identify and analyze appropriate jobs--including visual and auditory demands, mobility needs, communication needs, and specific work skills
  - ✓ Determine a schedule of visits that is individualized to the needs of the target youth and staff and allows opportunities to gather information on any unanswered questions on the vocational profile. Include several different job types and duties for each youth across 3-5 days, 3-4 hours per job type
  - ✓ Schedule assessments and inform appropriate jobsite personnel, school personnel, rehabilitation personnel, and family members and youth

- **Step #5: Review and Record Assessment Data**
  - ✓ Record information on a vocational profile form
  - ✓ Review assessment information and summarize the youth's preferences, needs, and suggestions. Provide feedback to service providers, family, and youth
  - ✓ Write follow-up and thank-you letters to the jobsites

What is an Example of a Form That Can be Used to Functionally Assess Youths Who Are Deaf-Blind?

- Table 6.1 is an example of a vocational profile and an assessment form that can be used to compile the results of vocational assessment activities. The form includes space for examining data from standardized tests, interviews and observations, and situational assessments. The form also includes questions sensitive to the communication, O&M, low vision and audiological needs of youths who are deaf-blind.

TABLE 6.1
Vocational Profile Form for Youths Who Are Deaf-Blind[1]

I. **Individual's Name:**_____ **Date of Assessment:**___/___/___

Date of Birth:___/___/___ **Social Security Number:**_____

Current Program or Status:_____

Brief Description of Disability:_____

_____

Contact Person:_____

Address:_____

Telephone Number:_____

Name of Person Completing Form:_____

Please check all sources of data information used to complete this assessment. Check all appropriate responses.

____school records

____psychological records

____medical records

____vocational records

____other (please specify)

_____

____interview

____interview with family member

____interview with friends or advocate

____ interview service provider

____other (please specify)

_____

____ observation in school setting

____ observations in vocational setting

____ observation in residential setting

____ observation in community setting

____ other (Please specify)

---

[1] *(Everson, Burwell, & Killam, 1995.) This form was adapted from: McLoughlin, Garner & Callahan (1987) and Moon, Goodall, Barcus & Brooke (1986). Much appreciation is expressed for the assistance of John Mascia and Alice Towne of the Helen Keller National Center (HKNC) Revised 8/94.*

II. Following a review of the individual's school, psychological, medical, and vocational records; interviews with the individual, family members, and service providers; and one or more observations of the individual in a variety of settings, indicate the most appropriate response(s) for each item. Please check <u>all</u> that apply. Please answer <u>each</u> question using all available information and data.

1. AVAILABILITY:

Will work weekends	Will work evenings	Will work part-time	Will work full time
_____	_____	_____	_____

Comments:_____

2. TRANSPORTATION:

Access to specialized transit services	Lives on bus route or subway route	Family will transport	Will walk	Will transport self
_____	_____	_____	_____	_____

Comments:_____

3. INDEPENDENT STREET CROSSING SKILLS:

None	Crosses 2 lane street with light	Crosses 2 lane street without light	Crosses 4 lane street with light	Crosses 4 lane street without light
_____	_____	_____	_____	_____

Comments:_____

4. INITIATIVE/MOTIVATION:

Avoids next task	Waits for directions	Sometimes volunteers	Always seek work
_____	_____	_____	_____

Comments:_____

5. STRENGTH: LIFTING AND CARRYING

Poor (4-9 lbs.)	Fair (10-25 lbs.)	Average (26-49 lbs.)	Strong (>50lbs.)
_____	_____	_____	_____

Comments:_____

6. ***ENDURANCE:***

Works < 2 hours; No breaks	works 2-3 hours; No breaks	Works 3-4 hours No breaks	Works > 4 hours; No breaks
_____	_____	_____	_____

Comments:_____

7. ***ORIENTATION:***

Small areas of a room only	One room	Several Rooms	Building Wide	Community Wide
_____	_____	_____	_____	_____

Comments:_____

8. ***MOBILITY:***

Uses sighted guide	Uses Trailing	Uses cane	Uses guide dog	Uses wheelchair/walker	Uses electronic travel aids
_____	_____	_____	_____	_____	_____

Comments:_____

9. ***INDEPENDENT MOVEMENT:***

Rarely moves independently	Moves easily in an empty room	With a few people/obstructions	In congested areas
_____	_____	_____	_____

Comments:_____

10. ***INDEPENDENT WORK RATE (WITHOUT PROMPTS OR CUES):***

Slow	Average steady pace	Above average/ sometimes fast	Continual fast pace
_____	_____	_____	_____

Comments:_____

11. APPEARANCE:

Unkept/poor hygiene	Unkept/good hygiene	Neat/clean but unmatched clothing	Neat/clean and matched clothing
_____	_____	_____	_____

Comments:_____

12. COMMUNICATION:

Uses gestures/ vocalizations	Uses basic signs	Uses communication cards/book/assistive devices	Communicates clearly in signs	Uses Speech
_____	_____	_____	_____	_____

Comments:_____

13. SOCIAL INTERACTIONS:

Responds inappropriately but infrequently	Responds appropriately but infrequently	Responds inappropriately and frequently	Responds appropriately and frequently
_____	_____	_____	_____

Comments:_____

14. UNUSUAL BEHAVIOR:

Many unusual behaviors	Few unusual behaviors	No unusual behaviors
_____	_____	_____

Comments:_____

15. ATTENTION TO TASK/PERSEVERANCE:

Frequent Prompts Required	Intermittent prompts/ high supervision required	Intermittent prompts/ low supervision required	Infrequent prompts/ low supervision required
_____	_____	_____	_____

Comments:_____

16. INDEPENDENT SEQUENCING OF JOB DUTIES:

Cannot perform tasks in sequence	Performs 2-3 tasks in sequence	Performs 4-6 tasks in sequence	Performs more than 7 tasks in sequence
_____	_____	_____	_____

Comments:_____

17. ADAPTING TO CHANGE:

Rigid routine required	Adapts to change with great difficulty	Adapts to change with some difficulty	Adapts to changes
_____	_____	_____	_____

Comments:_____

18. REINFORCEMENT NEEDS:

Frequent reinforcement throughout tasks	Reinforcement daily	Reinforcement weekly	Pay check sufficient reinforcement
_____	_____	_____	_____

Comments:_____

19. DISCRIMINATION SKILLS:

Cannot distinguish between work supplies even with tactual cue	Distinguishes between work supplies with a tactual cue	Distinguishes between work supplies without a tactual cue
_____	_____	_____

Comments:_____

20. TIME AWARENESS:

Unaware of time and clock function	Identifies breaks and lunch	Can tell time to the hour	Can tell time in hours and minutes
_____	_____	_____	_____

Comments:_____

21. ***FUNCTIONAL READING:***

None	Sight words/ symbols	Simple reading, print	Fluent reading, print	Reads Braille, Grade 1	Reads Braille, Grade 2
_____	_____	_____	_____	_____	_____

Comments:_____

22. ***FUNCTIONAL MATH:***

None	Simple Counting	Simple Addition/ Subtraction	Complex computational skills
_____	_____	_____	_____

Comments:_____

23. ***HANDLING CRITICISM/STRESS:***

Resistant/ Argumentative	Withdraws into silence	Accepts Criticism/does change behavior	Accepts criticism/ changes behavior
_____	_____	_____	_____

Comments:_____

24. ***ACTS/SPEAKS AGGRESSIVELY:***

Hourly	Daily	Weekly	Monthly	Never
_____	_____	_____	_____	_____

Comments:_____

25. ***DISTANCE VISION:***

Can visually locate or read:	*Not at all*	*5 feet*	*10 feet*	*20 feet*
• Large objects (furniture, people)	_____	_____	_____	_____
• Small objects (food items, work pieces)	_____	_____	_____	_____
• Indoor/outdoor signs (restroom, office numbers, exit)	_____	_____	_____	_____

Comments:_____

26. *DEPTH PERCEPTION*

When reaching for an object:

Needs many tries to get it _____ Needs a few tries _____ Gets it on first try _____

Comments:_____

27. *VISUAL FIELDS*

When walking:	Very Often	Sometimes	Rarely
• Trips over curbs, uneven walkways; uneasy on stairs	_____	_____	_____
• Bumps into walls, other people, protruding objects	_____	_____	_____

Comments:_____

28. *NEAR VISION*

Can see/read/identify visually:

watch _____
clock _____
paper money _____
coins _____
telephone directory _____
price tags _____
newspaper headlines _____
newspaper print _____
computer screen _____
other _____

Comments:_____

29. *LIGHTING:*

Has difficulty with:

bright light/glare _____
dimly lit areas _____
adjusting to change in lighting _____
night blindness _____

Comments:_____

30. ***COLORS:***

identifies colors _____

confuses similar colors (e.g., blue & black) _____

sees better of background is contrasting color _____

Comments:_____

31. ***FUNCTIONAL HEARING:***

Can't hear speech at all	Can hear speech only when shouted	Can hear speech at a normal speech level	Can hear speech in a whisper
_____	_____	_____	_____

Comments:_____

32. ***TO AUGMENT HEARING:***

Uses hearing aid/other assistive device	Uses lipreading	Uses Sign (ASL, signed English)	Uses Tadoma
_____	_____	_____	_____

Comments:_____

33. ***HAS DIFFICULTY HEARING:***

In a noisy environment	In right ear	In left ear	Woman's voices	Men's voices
_____	_____	_____	_____	_____

Comments:_____

III. PLEASE SUMMARIZE ALL AVAILABLE DATA AND INFORMATION TO RESPOND TO EACH OF THESE AREAS.

1. ***Medical History (Describe vision and hearing loss and medical stability)***

2. ***Residential History:***

3. *Family Support Available:*

4. *Financial Needs of Applicant:*

5. *Friends and Social Group:*

6. *General Employment Near Home:*

7. *Informal Work Performed at Home:*

8. *Paid Employment Experiences:*

9. *Type of work the applicant wants to do:*

IV. DESCRIPTION OF "IDEAL" EMPLOYMENT SITUATION

(This is a composite, narrative or graphic description based on input by applicant, parents/guardians, service agency staff, and data information from assessment).

TABLE 6.2

WHAT TYPES OF JOBS CAN PEOPLE WHO ARE DEAF-BLIND DO?	
CUSTODIAN	HOUSEKEEPER
LIBRARIAN	SMALL PARTS ASSEMBLER
FACTORY CREW PERSON	OFFICE WORKER
BAKER'S ASSISTANT	RESTAURANT ATTENDANT
DRAFTPERSON	BUSPERSON
LAUNDRY WORKER	PAYMENT PROCESSOR
CASHIER	ANY OTHER JOBS IDENTIFIED BY CREATIVE JOB DEVELOPERS!

(Jobs identified by HKNC and VCU-RRTC, 1992)

TABLE 6.3

HOW TO ANALYZE A JOB FOR A YOUTH WHO IS DEAF-BLIND	
✓	USE A FORM TO ENSURE THAT ALL CRITICAL INFORMATION IS GATHERED AND RECORDED
✓	ANALYZE JOB TASKS AND REQUIREMENTS
✓	ANALYZE VISUAL AND AUDIOLOGICAL REQUIREMENTS
✓	ANALYZE ORIENTATION & MOBILITY REQUIREMENTS
✓	ANALYZE COMMUNICATION REQUIREMENTS
✓	ANALYZE ACADEMIC SKILL REQUIREMENTS
✓	ANALYZE EQUIPMENT REQUIREMENTS

TABLE 6.4

Job Analysis Form for Youths Who are Deaf-Blind[2]

I. **Company's Name:** _____ **Date of Assessment:** ___/___/___

Address: _____

Telephone Number: _____

Type of Assessment: _____**initial**_____**on-going**

Company Contact Person: _____

Title: _____

Job Tile of Assessed Job (Please complete one form for <u>each</u> assessed job): _____

_____

Available Job Description:

_____No
_____Yes (If yes, please attach to the back of this form)

Please check all sources used to develop this job. Check <u>all</u> appropriate responses.

_____newspaper classified advertisement

_____sign in window of businesses

_____referral by other employment provider

_____referral by other employer

_____referral by parent

_____"cold call" or "drop-in visit"

_____other (please specify)

_____

[2] *(Everson, Burwell & Killam, 1995) This form was adapted from: McLoughlin, Garner, & Callahan (1986) and Moon, Goodall, Barcus & Brooke (1986). Much appreciation is expressed for the assistance of John Mascia and Alice Towne of the Helen Keller National Center (HKNC). Revised 8/94*

II. **Following an interview with the employer; and one or more observations at the company, please summarize all available data and information to respond to each of these areas. Please check <u>all</u> appropriate responses and complete <u>each</u> section using all available information and data.**

1. ***DESCRIPTION OF JOB DUTIES:***

Specific Job Duty	Appropriate Time	Work Schedule (e.g., M-F, Saturday only, etc.)
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

2. ***NUMBER OF REQUIRED HOURS PER WEEK FOR POSITION:*** _____

3. ***COMPANY BENEFITS:***

____none
____health insurance
____dental insurance
____vision insurance
____life insurance
____vacation leave
____sick leave
____employee discounts
____free or discounted meals
____other (Please specify)

_____

4. ***NUMBER OF EMPLOYEES IN COMPANY:***

Number of Employees in Specific Position: _____

Number of Employees in General Work Area: _____

Availability of Supervision: _____

Estimated Position Turnover Rate: _____

Productivity Requirements: _____

5. ***SUPERVISOR'S PET PEEVES OR "DON'TS":*** _____

_____

_____

6. ***ATMOSPHERE OF BUSINESS SITE (e.g., PACE OF WORK, "CULTURE", etc.):*** _____

_____

_____

7. ***MACHINERY, TOOLS, OR EQUIPMENT OPERATION REQUIRED:*** _____

_____

_____

8. ***SPECIAL TERMS USED:*** _____

_____

_____

Comments: _____

9. ***SPECIAL CLOTHING OR UNIFORM REQUIRED:*** _____

_____

10. ***TRAINING AVAILABLE FROM BUSINESS:*** _____

_____

11. ***RECEPTIVITY TO "JOB COACH" SERVICES:*** _____

_____

12. ***VISIBILITY TO PUBLIC:*** _____

III. INDICATE THE MOST APPROPRIATE RESPONSE(S) FOR EACH ITEM. PLEASE CHECK ALL THAT APPLY.

PLEASE ANSWER EACH QUESTION USING ALL AVAILABLE INFORMATION AND DATA.

1. ***SCHEDULE:***

Must work weekends	Must work evenings	Must work part-time	Must work full time
_____	_____	_____	_____

Comments:_____

2. ***TRANSPORTATION LOCATION:***

On public transportation route	On specialized transportation route
_____	_____

Comments:_____

3. ***STREET CROSSING:***

None required	Must cross 2 lane street with light	Must cross 2 lane street without light	Must cross 4 lane street with light	Must cross 4 lane street without light
_____	_____	_____	_____	_____

Comments:_____

4. ***INITIATION OF WORK/MOTIVATION:***

Initiation of work required	Volunteering helpful	Staff will prompt to next task	Natural cue or prompts available
_____	_____	_____	_____

Comments:_____

5. ***STRENGTH: LIFTING AND CARRYING***

Very light work (<9lbs.)	Light work (10-25 lbs.)	Average work (26 - 49 lbs.)	Heavy work (>50 lbs.)
_____	_____	_____	_____

Comments:_____

6. ***ENDURANCE: (NO BREAKS)***

Work required for <2 hours	Work required for 2-3 hours	Work required for 3-4 hours	Work required for >4 hours	Reads braille, not print
_____	_____	_____	_____	_____

Comments:_____

7. ***ORIENTING:***

Small areas of one room only required	One room required	Several rooms required	Building wide required	Community wide required
_____	_____	_____	_____	_____

Comments:_____

8. ***MOBILITY:***

May use sighted guide	May use trailing	May use cane	May use guide dog	May use wheelchair/ walker	May use electronic travel aids
___	___	___	___	___	___

Comments:_____

9. ***INDEPENDENT MOVEMENT:***

Independent movement at all times required	Some independent movement required	Independent movement with few people/obstructions required	Independent movement in congested areas required
_____	_____	_____	_____

Comments:_____

10. ***INDEPENDENT WORK RATE (WITHOUT PROMPTS OR CUES):***

Slow rate required	Average steady pace required	Above average/ sometimes fast pace required	Continual fast pace required
_____	_____	_____	_____

Comments:_____

11. ***APPEARANCE:***

Grooming of little importance	Good hygiene only required	Neat/clean and uniform or specific clothing required	Neat/clean and matched clothing required
_____	_____	_____	_____

Comments:_____

12. ***COMMUNICATION:***

None/minimal required	Basic signs acceptable	Communication cards/book/assistive devices acceptable	Communication clearly in signs acceptable	Speech required
_____	_____	_____	_____	_____

Comments:_____

13. ***SOCIAL INTERACTIONS:***

Social interactions not required	Appropriate social responses required infrequently	Appropriate social interactions required frequently	Appropriate social interactions required continuously
_____	_____	_____	_____

Comments:_____

14. ***UNUSUAL BEHAVIOR:***

Many unusual behaviors acceptable	Few unusual behaviors acceptable	No unusual behaviors acceptable
_____	_____	_____

Comments:_____

15. ***ATTENTION TO TASK/PERSEVERANCE:***

Frequent prompts/high supervision available	Intermittent prompts/ high supervision available	Intermittent prompts/ low supervision available	Infrequent prompts/ low supervision
_____	_____	_____	_____

Comments:_____

16. ***INDEPENDENT SEQUENCING OF JOB DUTIES:***

Only one task required at a time	2-3 tasks required in sequence	4-6 tasks required in sequence	7 or more tasks required in sequence
_____	_____	_____	_____

Comments:_____

17. ***CHANGES IN ROUTINE:***

Rigid daily routine required	7 or more changes required daily	4-6 changes required daily	2-3 changes required daily	No daily changes	Weekly changes only
_____	_____	_____	_____	_____	_____

Comments:_____

18. ***REINFORCEMENT AVAILABILITY:***

Frequent reinforcement throughout tasks	Reinforcement daily	Reinforcement weekly	Pay check only reinforcement
_____	_____	_____	_____

Comments:_____

19. ***DISCRIMINATION REQUIREMENTS:***

Must distinguish between work supplies without tactual cues	May distinguish between work supplies with some tactual cues	May distinguish between work supplies with lots of tactual cues
_____	_____	_____

Comments:_____

20. ***TIME AWARENESS:***

Time factors not important	Must identify breaks/meals etc.	Must sell time to the hour	Must tell time to the minute
_____	_____	_____	_____

Comments:_____

21. ***FUNCTIONAL READING:***

None required	Sight words/ symbols required	Simple reading required	Fluent reading required	Braille, not print acceptable
____	____	____	____	____

Comments:_____

22. ***FUNCTIONAL MATH:***

None required	Simple counting required	Simple addition/ subtraction required	Complex computational skills required
____	____	____	____

Comments:_____

23. ***EMPLOYER ATTITUDE:***

Very supportive of workers with deaf-blindness/likes concept of supported employment	Supportive with reservations	Negative toward workers with deaf-blindness/likes concept of supported employment	Negative toward supported employment supportive of workers who are deaf-blind
____	____	____	____

Comments:_____

24. ***DISTANCE VISION REQUIREMENTS:***

Must be able to visually locate and/or read:	Not at all	5 feet	10 feet	20 feet
•Large objects (furniture, people)	____	____	____	____
•Small objects (food items, work pieces)	____	____	____	____
•Indoor/outdoor signs (restroom, office numbers, exit)	____	____	____	____

Comments:_____

25. DEPTH PERCEPTION REQUIREMENTS:

When reaching for an object:

May use many tries to get it	May use a few tries	Must get it on first try
_____	_____	_____

Comments:_____

26. VISUAL FIELD REQUIREMENTS:

When walking must be able to:	Very often	Sometimes	Rarely
•Step over curbs, uneven walkways; use on stairs	_____	_____	_____
•Avoid walls, other people, protruding objects	_____	_____	_____

Comments:_____

27. NEAR VISION REQUIREMENTS:

Must be able to read/identify visually:

watch _____

clock _____

paper money _____

coins _____

telephone directory _____

price tags _____

newspaper headlines _____

newspaper print _____

computer screen _____

other_____

Comments:_____

28. *LIGHTING REQUIREMENTS:*

Requires ability in:

bright light/glare _____

dimly lit areas _____

adjusting to change in lighting _____

night vision _____

Comments:_____

29. *COLOR REQUIREMENTS:*

requires ability to identify colors _____

discriminates similar colors (blue & black) _____

see even background is contrasting color _____

Comments:_____

30. *FUNCTIONAL HEARING:*

Must hear speech clearly	May hear speech only when shouted	May hear speech at a normal speech level	May hear speech in a whisper
_____	_____	_____	_____

Comments:_____

31. *TO AUGMENT HEARING:*

May use hearing aid/ other assistive device	May use lipreading	May use sign (ASL, signed English)	May use Tadoma
_____	_____	_____	_____

Comments:_____

32. *TO DISCRIMINATE HEARING:*

Must hear a noisy environment	Must hear in right ear	Must hear in left ear	Must hear woman's voice	Must hear men's voice

TABLE 6.5
Jobsite Training Strategies For Youths Who Are Deaf-Blind

1. Always orient the worker to new settings, materials, and activities.

2. Know how to best communicate with the worker and model and teach these methods to co-workers and the general public.

3. Ensure optimal positioning of the worker for most efficient use of residual auditory and visual skills.

4. Always use task analyses to test and teach specific job and related job skills.

5. Although it is always most desirable to have a worker respond to naturally occurring stimuli, for most workers who are deaf-blind, it will be more efficient to provide a planned system of prompts and cues.

6. Selection of prompts and cues should consider the worker's type of visual and hearing losses, amount and type of residual hearing and/or vision, age of onset of the sensory losses, communication methods, and related disabilities (if any).

7. Prompts and cues include signed or tactual instruction, tactual cues, enhanced visual and/or auditory cues, model prompts, physical prompts, large print or brailled cues, enlarged photographs, low vision aids, hearing aids, assistive listening devices, and other assistive technology.

8. Prompts and cues should be defined as either permanent or temporary: remember all temporary cues and prompts must be faded along with the job coach or other employment personnel. Before presenting a temporary cue or prompt, know how you are going to fade it! Before presenting a permanent cue or prompt, ensure that it is site- and age-appropriate!

9. Choose an instructional format including a system of least-to-most intrusive prompts and/or, time delay combined with whole task instruction, backward chaining, or forward chaining.

10. For individuals who have significant visual impairments or who are blind, but have some residual hearing, combine auditory prompts with tactual cues and prompts.

11. For individuals who have profound hearing losses or who are deaf, but have some residual vision, combine signed instruction with model prompts, enlarged visual cues, and physical prompts.

12. For individuals who are profoundly deaf and legally blind, combine tactual instruction and cues with physical prompts.

13. Always consider the use of natural supports for job skill training, O&M assistance, and general communication.

14. Always include the wants and needs of the worker, especially when considering assistive technology, communication strategies, and use of natural supports.

EMPLOYMENT QUALITY INDICATORS CHECKLIST

- Table 6.6, on the following pages, was designed by HKNC-TAC staff and consultants to guide educators in assessing the individualization and appropriateness of employment programming for a youth who is deaf-blind. It may be used to assess a program before a youth is referred to it for services, to develop a job and support plan, or to develop a technical assistance request application from an appropriate provider.

TABLE 6.6

Helen Keller National Center - Technical Assistance Center (HKNC-TAC)

Employment Quality Indicators Checklist

Student's Name: _____ Student's Date of Birth: _____ Telephone Number: (____)

Name of Program: _____ Service Provider or Teacher's Name: _____

Type of Assessment: ( ) Initial ( ) Ongoing Date of Assessment: _____ (M/D/Y) Person Completing Assessment: _____

Quality Indicator	Assessment Method R = Review of Records O= Observation of Student I = Interview with Service Provider and/or Family S = Administration of standardized assessment F = Administration of functional or teacher-made assessment	Rating of Indicator 0 = Not applicable to student 1 = No evidence in student's program 2 = Little, uneven, and/or inconsistent evidence in student's program 3 = Substantial, even, and consistent evidence in student's program	Technical Assistance Need L = Low priority need M = Medium priority need H = High priority need
I. CONSUMER ASSESSMENT			
A. Key service providers are interviewed (e.g., education providers, vocational trainers, current employers, residential care providers, etc.)	R O I S F	0 1 2 3	L M H
B. Parents/family members are interviewed	R O I S F	0 1 2 3	L M H
C. Individual who is deaf-blind is interviewed	R O I S F	0 1 2 3	L M H
D. Individual who is deaf-blind is observed in current program/settings	R O I S F	0 1 2 3	L M H
F. All medical, audiological, opthalmolological, educational, psychological, and vocational records are reviewed and updated	R O I S F	0 1 2 3	L M H
F. Functional orientation and mobility (O&M) assessments are conducted	R O I S F	0 1 2 3	L M H
G. Functional vision and hearing assessments are conducted	R O I S F	0 1 2 3	L M H
H. Future employment dreams and preferences are assessed (e.g., PFP maps, vocational profiles)	R O I S F	0 1 2 3	L M H
I. (As needed), community-based, situational assessments are conducted	R O I S F	0 1 2 3	L M H
J. All assessment information is functionally interpreted and organized in a written assessment form or functional profile	R O I S F	0 1 2 3	L M H

Quality Indicator	Assessment Method R = Review of Records O= Observation of Student I = Interview with Service Provider and/or Family S = Administration of standardized assessment F = Administration of functional or teacher-made assessment	Rating of Indicator 0 = Not applicable to student 1 = No evidence in student's program 2 = Little, uneven, and/or inconsistent evidence in student's program 3 = Substantial, even, and consistent evidence in student's program	Technical Assistance Need L = Low priority need M = Medium priority need H = High priority need
I. CONSUMER ASSESSMENT (continued)			
K. Assessment procedures are conducted in collaboration with rehabilitation services agency and assist in determining type and scope of services (e.g., transitional, supported, etc.)	R O I S F	0 1 2 3	L M H
II. JOB DEVELOPMENT			
A. Labor market is analyzed to identify key occupational clusters available locally	R O I S F	0 1 2 3	L M H
B. From this analysis, several occupational clusters are identified that reflect the individual who is deaf-blind's dreams and preferences	R O I S F	0 1 2 3	L M H
C. Contacts are made with potential employers and characteristics of deaf-blindness are explained	R O I S F	0 1 2 3	L M H
D. A through, written job analysis is completed for each potential job, including: 1) sequence of job duties; 2) visual requirements; 3) audiological requirements; 4) travel requirements; 5) O&M requirements; 6) communication requirements; 7) job skill requirements; 8) physical requirements; 9) equipment requirements; and 10) availability of natural supports	R O I S F	0 1 2 3	L M H
E. The individual who is deaf-blind participates in the job development process	R O I S F	0 1 2 3	L M H
III. JOB PLACEMENT			
A. Individual is matched to one or more jobs using a combination of assessment and job development information	R O I S F	0 1 2 3	L M H
B. If a job placement is not secured through the matching process, them mechanisms for continued assessment and job development are conducted	R O I S F	0 1 2 3	L M H
C. Job placement activities are comprehensive (e.g., include family notification, social security notification; transportation arrangements and emergency procedures)	R O I S F	0 1 2 3	L M H

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Quality Indicator	Assessment Method R = Review of Records O= Observation of Student I = Interview with Service Provider and/or Family S = Administration of standardized assessment F = Administration of functional or teacher-made assessment	Rating of Indicator 0 = Not applicable to student 1 = No evidence in student's program 2 = Little, uneven, and/or inconsistent evidence in student's program 3 = Substantial, even, and consistent evidence in student's program	Technical Assistance Need L = Low priority need M = Medium priority need H = High priority need
D. The impact of employment on social security benefits and medical benefits is accurately examined and explained to the individual who is deaf-blind and his or her family	R O I S F	0 1 2 3	L M H
IV JOB TRAINING AND SUPPORT			
A. Written task analyses/instructional sequences (e.g., prompt, probes, reinforcement) are available	R O I S F	0 1 2 3	L M H
B. Task analyses/instructional sequences attend to vision enhancing and glare-reducing instruction/modifications/devices	R O I S F	0 1 2 3	L M H
C. Task analyses/instructional sequences attend to O&M instruction/modifications/devices	R O I S F	0 1 2 3	L M H
D. Task analyses/instructional sequences attend to communication instruction/modifications/devices	R O I S F	0 1 2 3	L M H
E. Transportation plans are in place and monitored	R O I S F	0 1 2 3	L M H
F. Emergency plans (e.g., fires, safety, etc.) are in place and monitored	R O I S F	0 1 2 3	L M H
G. Co-workers and other natural supports are attended to along with task analyses/instructional sequences	R O I S F	0 1 2 3	L M H
H. Interpreters are available (as needed)			
I. Job coaches are available (as needed)	R O I S F	0 1 2 3	L M H
V. EXTENDED AND FOLLOW-ALONG SERVICES			
A. Skill maintenance/generalization plans are in place and are monitored for all job skills	R O I S F	0 1 2 3	L M H
B. Vision, hearing, and O&M plans are in place and are monitored	R O I S F	0 1 2 3	L M H
C. Communication plans are in place and are monitored	R O I S F	0 1 2 3	L M H
D. Funding and staff for extended and follow-along services are in place and are monitored	R O I S F	0 1 2 3	L M H

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Quality Indicator	Assessment Method R = Review of Records O= Observation of Student I = Interview with Service Provider and/or Family S = Administration of standardized assessment F = Administration of functional or teacher-made assessment	Rating of Indicator 0 = Not applicable to student 1 = No evidence in student's program 2 = Little, uneven, and/or inconsistent evidence in student's program 3 = Substantial, even, and consistent evidence in student's program	Technical Assistance Need L = Low priority need M = Medium priority need H = High priority need
E. Social security work benefits/work incentives and medical benefits are monitored at least annually	R O I S F	0 1 2 3	L M H
F. Employer satisfaction is monitored at least quarterly	R O I S F	0 1 2 3	L M H
G. Employee satisfaction is monitored at least quarterly	R O I S F	0 1 2 3	L M H
H. Employee skills are monitored quarterly (or as needed)	R O I S F	0 1 2 3	L M H
I. O&M skills, travel, and emergency plans are evaluated at least annually	R O I S F	0 1 2 3	L M H
J. Communication plans are evaluated quarterly (or as needed)	R O I S F	0 1 2 3	L M H
K. Program maintains regular contact with family, home, medical and other vocationally related services	R O I S F	0 1 2 3	L M H
IV. PROGRAM POLICIES AND PROCEDURES			
A. Program eligibility and referral procedures include applicants who are deaf-blind	R O I S F	0 1 2 3	L M H
V. PROGRAM POLICIES AND PROCEDURES (CONCLUDED)			
B. Staff training includes communication, vision, hearing, and O&M training	R O I S F	0 1 2 3	L M H
C. Staff training includes first aid and medical training	R O I S F	0 1 2 3	L M H
D. Positive behavior management policies and procuress are in place	R O I S F	0 1 2 3	L M H

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CHAPTER SEVEN
Developing Recreation and Leisure Time Opportunities for Youths Who are Deaf-Blind

☞ *by Kathleen McNulty*

WHY ARE RECREATION AND LEISURE TIME OPPORTUNITIES SO IMPORTANT FOR YOUTHS WHO ARE DEAF-BLIND?

- Recreation and leisure education is an important component of transition services for youths who are deaf-blind. When incorporated into the youth's IEP/statement of transition services, recreation and leisure education can provide youths and their families with:
  - → knowledge of community resources;
  - → skills needed to participate in recreation and leisure activities in community and home environments;
  - → communication skills necessary to make choices about how to spend leisure time;
  - → activity-based opportunities to spend pleasurable time practicing and expanding communication and choice-making skills; and
  - → opportunities to experience fuller and richer community presence, to make friends, and enhance employability (Scola, 1984).

WHAT GUIDELINES SHOULD BE FOLLOWED WHEN DEVELOPING RECREATION AND LEISURE PROGRAMS FOR YOUTHS WHO ARE DEAF-BLIND?

- There are five guidelines to consider when developing recreation and leisure programs for youths who are deaf-blind (McNulty, Mascia, Roccio, & Rothstein, 1995):
  - → Establish communication and rapport.
  - → Use person-centered planning as an assessment technique.
  - → Assess community leisure and recreation opportunities.
  - → Provide appropriate instruction.
  - → Identify and furnish supports.

How can Information be Gathered to Ensure the Individual's Preferences, Talents and Capacities are Considered?

- A person-centered approach to planning (O'Brien, 1987; Mount, 1991) is an especially meaningful recreation assessment tool for the deaf-blind population.Getting to know a person begins by simply asking questions of the youth who is deaf-blind and of other individuals who know the person well. This is where the time spent establishing communication and rapport will become clear. Interview deaf-blind youths, their friends and same-age peers, their family members, and service providers.

- **Here are questions to consider:**
  - → What experiences has this person had in the past?
  - → What are this person's likes and dislikes?
  - → What things seem to work for this person?
  - → What things don't seem to work?

- Record everything that is mentioned or described, even those things that may appear to be insignificant at first. **Table 7.1 (McNulty et al., 1995) provides an example of a recording form that might be used to record information gathered during these interview activities.**

TABLE 7.1

Things that Work for ... (Name of Individual)	**Things that Don't Work for ...** (Name of Individual)

- In addition to identifying leisure and recreational preferences, it will also be helpful to identify information on the person's ability to access and participate in recreation activities. **This includes information such as:**
  - → (1) communication methods and abilities;
  - → (2) amount and type of residual hearing;
  - → (3) amount and type of residual vision;
  - → (4) orientation and mobility (O&M) needs and community travel skills; and
  - → (5) medical and health needs.

- Interviews will assist with obtaining some of this information. Reviews of medical and educational records, observations in classrooms, community-based training sites, home visits, and situational assessments in recreational settings are additional sources of assessment data. **Table 7.2 (McNulty et al., 1995) is an example of a profile form that can be used to collect this type of assessment information.**

TABLE 7.2

Things to Consider	What We Know About _____
Communication Methods and Abilities	
Residual Hearing	
Residual Vision	
Orientation & Mobility Needs and Travel Skills	
Medical and Health Considerations	

- **The questions below (McNulty et al., 1995) are examples of the type of questions you might want to ask when gathering information to complete Table 7.2:**

  - → **Hearing**
  - ✓ Does the person have any residual hearing?
  - ✓ Is the hearing loss in one or both ears?
  - ✓ How does the person receive meaningful information about the environment?
  - ✓ How does the person use environmental information?
  - ✓ Are hearing aids or assistive listening devices useful? If yes, what types?
  - ✓ Are there certain settings that enhance or diminish hearing?

→ **Vision**

✓ Does the person have any residual vision? If so, how much and what type?
✓ How does the person receive meaningful information about the environment?
✓ How does the person use environmental information?
✓ Are low vision or optical aids used? If yes, what types?
✓ Are there certain settings that enhance or diminish vision?

→ **Communication**

✓ How does the individual communicate?
✓ Is ASL or SEE used?
✓ Is signing visual or tactual?
✓ Is print-on-palm used?
✓ Is speech understandable by the general public?
✓ Are augmentative or alternative communication devices used? If so, what types?
✓ Are non-symbolic communication methods used? If so, what methods and patterns are most successful?
✓ Is braille or large-print used?

→ **Orientation & Mobility**

✓ Is the person able to orient within one or two rooms? in large buildings or centers?
✓ Are there balance problems?
✓ Does the person use protective techniques?
✓ Is sighted guide needed?
✓ Are other assistive mobility devices used?
✓ Is the person able to travel independently?
✓ Can he/she travel independently in familiar surroundings?
✓ Can public transportation be used?
✓ Can he person use emergency evaluation procedures?
✓ Can the person request or refuse assistance from the general public? What type of routes can be traveled safely?

→ **Medical and Health Considerations**

✓ Is the person generally in good health?
✓ How is the person's physical strength and endurance?
✓ Are there any existing medical or health conditions that would prohibit or restrict certain recreational or leisure activities? Are there any medical or dietary considerations?

How Can a Community Profile of Recreation and Leisure Time Resources Be Developed?

- Once the individual's preferences, abilities, and support needs have been assessed, the next step is to assess the leisure and recreation opportunities available in the youth's local community. Read newspapers, telephone directories, church and recreation center newsletters and flyers. Visit libraries, community fairs, civic groups, community colleges, community businesses and associations. Be flexible and creative in identifying opportunities and remember that leisure and recreation opportunities occur in homes, community centers, schools and other settings. In addition, they involve both individual and group activities.

- One overlooked community resource are "interest sites" which Beth Mount defines as "untapped opportunities for social interaction for persons with disabilities." (B. Mount, personal communication, July, 1992). Every community has a commercial enterprise where groups of adolescents and young adults like to spend leisure time. For example, shops that sell motorcycles, running shoes, specialized kites, used books, coffee and pastries, or surfing equipment are often community interest sites. Customers typically spend time in these stores socializing. Interest sites should be assessed closely for their recreation and leisure potential.

- Table 7.3 (McNulty et al., 1995) is an example of a form which can be used to develop a community resource profile. **For each identified community resource, ask:**
  - ✓ What recreation services and activities are available?
  - ✓ What are the time cost, and equipment requirements?
  - ✓ Are there activities that do not require any fees, or that might waive fees, or provide scholarships?
  - ✓ Are there any possible modifications to the activity or assistive devices that might be used?
  - ✓ Are there any therapeutic recreation staff, leisure coaches, volunteers, or peer supports who may be used?
  - ✓ Is the program physically accessible?
  - ✓ Is transportation available and accessible?
  - ✓ Are there possible adaptations to the environment?

TABLE 7.3
Community Resource Profile

Resources in the Community	What Needs to be Done to Access this Resource
Interest Sites	
Motorcycle Shop	
Kite Shop	
Sporting Good's Store	
Music Store	
Surf Shop	
Ski Shop	
Used Book Store	
Other:	
Resources Operated by Local Government	
Adult Education Classes -	
Cooking	
Art	
Music	
Dance	
Computers	
Yoga	
Marshal Arts	
Crafts	
Jewelry Making	
Knitting/Crocheting	

Resources in the Community	What Needs to be Done to Access this Resource
Sewing	
Quilting	
Frame Loom Weaving	
Sign Language	
Creative Writing	
Typing/Word Processing	
Theater Guild	
Photography	
Other	
Recreation Department Programs	
Swimming	
Roller Skating	
Track and Field	
Ice Skating	
Golf	
Exercise Classes	
Jogging	
Day Trips	
Overnight Trips	
Festivals	
Fairs/Carnivals	
Tournaments	
Dances	
Other	

Resources in the Community	What Needs to be Done to Access this Resource
Recreational Facilities:	
Public Pool	
Parks	
Town Beach	
Ball Fields	
Tennis Courts	
Golf Course	
Gym	
Steam-bath/Sauna	
Other	
Public Transportation Department:	
Bus	
Train	
Other	
Resources Owned and Operated by Private Sector:	
Movie Theaters	
Restaurants	
Stores	
Health Clubs	
Bowling Alley	
Skating Rink	
Miniature Golf	
Billiard Parlor	
Other	

Resources in the Community	What Needs to be Done to Access this Resource
Community Organizations/Clubs/Associations:	
4H Club	
Scouts	
Running Club	
Kiting Club	
Stamp Collectors Club	
Chess Club	
Bridge Club	
Dining Club	
Theater Club	
Walking Club	
Other	

What Are Some Things That Should Be Remembered When Providing Instruction During a Recreation or Leisure Time Activity?

- Once a variety of recreational opportunities have been selected, training and support must be provided both to individuals who are deaf-blind, to program staff, and to general community members. Because of their limited experiences and communication support needs, many individuals with dual sensory impairment will need systematic instruction to enable them to choose, access, and enjoy recreation opportunities. **When providing instruction to an individual during a recreation or leisure activity, it should be remembered to:**

  → Experience the environment -
  - ✓ provide as much signed and/or tactual information as possible;
  - ✓ give descriptions of the immediate environment;
  - ✓ assist in exploring the environment;
  - ✓ look for landmarks when appropriate.

  → Provide systematic individualized instruction which utilizes such strategies as:
  - ✓ responding to naturally occurring stimuli;
  - ✓ using external prompts;
  - ✓ providing numerous examples of activities;
  - ✓ time delay with whole task instruction;
  - ✓ backward chaining; forward chaining;

  and, when appropriate
  - ✓ combining auditory prompts with tactual instruction cues;
  - ✓ combining instruction with model prompts and physical prompts;
  - ✓ combining tactual instruction and cues with physical prompts.

- Look for opportunities for the person to partially participate and or share in the experience when the activity can not be performed independently. Family, friends, or service providers complete any portion(s) of the activity which the individual can not complete, but are essential for completion of the activity. Thus, individuals with the most significant disabilities do not face any prerequisite skills or waiting period prior to actually participating in and enjoying recreational activities.

What are Examples of Supports That Might be Used in a Recreational or Leisure Time Setting?

- Maintaining a rich leisure time and recreation repertoire for the young adult who is deaf-blind can be extremely challenging. Identifying and furnishing individualized supports will almost always be required. **Examples of such supports include:**
  - → companionship and the interaction with another person
  - → one-to one assistance
  - → consistent transportation to and from a recreation site
  - → adequate interpreter services

- The use of aids and devices and the modification and adaptation of recreation materials and activities are examples of two other types of support that can be offered to the deaf-blind individual. Most individuals with dual sensory impairment have some residual hearing and/or vision. Hearing, vision, and communication can be improved during many recreational activities through the use of hearing aids, assistive listening devices, low vision aids and devices and appropriate environmental strategies. An audiologist, low vision specialist, and other team members can assist in choosing the most appropriate aids, devices, and strategies.

- Modifications include any additional cues or changes that enable the individual to understand the activity more fully. Individuals with dual sensory impairment typically benefit from tactual cues, but some individuals may also benefit from enhanced visual and/or auditory cues. Many modifications require little more than common sense and readily available materials. Rules can be changed, boundaries can be reduced, equipment can be modified:

Activity	Modification
Cooking	Recipe book in large print Velcro start button on microwave Use trays for boundaries
Jogging	Using a track with a guide rail Jogging with a partner
Painting	Adding textures to paint; e.g. sand, gravel

References and Suggested Readings

Dattilo, J. & St. Peter, S. (1991). A model for including leisure education in transition services for young adults with mental retardation. Education and Training in Mental Retardation 26(4). 420-432.

McNulty, K., Mascia, J., Roccio, L., & Rothstein, R. (1995) Developing leisure and recreation opportunities. In J.M. Everson (Ed.), Supporting young adults with deaf-blindness in their communities. A transition planning guide for service providers, family members, and friends. Baltimore: Paul H. Brookes.

Moon, M. S. (Ed.) (1994). Making school and community recreation fun for everyone. Places and ways to integrate. Baltimore: Paul H. Brookes.

Schleien, S & Ray, M. (1988). Community recreation and persons with disabilities. Baltimore: Paul H. Brookes.

CHAPTER EIGHT

Transitioning To Postsecondary Education Opportunities For Youths Who Are Deaf-Blind

☞ *by JoAnn Enos*

- Postsecondary education is an important option to consider for all youths who desire further learning opportunities after high school. Choices include adult education classes, technical or vocational colleges, local community colleges, as well as state and private colleges and universities. Each option has unique entrance and eligibility criteria, as well as programs of study.

- Although many youths who are deaf-blind should consider postsecondary education, currently very few youths who are deaf-blind actually transition from high school to postsecondary education opportunities (Wagner, 1993).

- What can educators do to increase postsecondary education opportunities for youths who are deaf-blind? Teachers, guidance counselors, families, and youths themselves may find discussions about future wants and needs a good place to start. Table 8.1 presents some examples of discussion topics.

TABLE 8.1
Thinking About Postsecondary Opportunities

Thinking About Postsecondary Education
1. What are your favorite classes? Why do you think you're successful in these classes?
2. What are your least favorite classes? Why do you think you are having difficulty in these classes?
3. How will the classes you are taking now help you reach your dreams?
4. Are you interested in attending college? How will it help you achieve your dreams?
5. What specific skills do you need that you could learn while you are still in high school?
6. How will you pay for college?
7. What support services do you think you will need in college? For example: interpreters, visual aids, audiological aids, and orientation and mobility instruction? How do you feel about using these services?

Thinking About Employment

1. What job would you like to be doing two years from now? Five years from now? Ten years from now?

2. What kind of work experiences have you had?

3. What skills will you need to do the kind of job you want to do? What kind of training or education do you need for this kind of job?

4. What things are important to you in a job? For example; salary, benefits, transportation, schedule, location, and personality of your boss?

5. What hobbies and interests do you have that might be related to a future job?

6. How can service providers help you get a job? How can family members and friends help you get a job?

Thinking About Living Arrangements

1. What does your dream house look like?

2. What kind of chores do you do at home that will help you live more independently? What kind of chores do you need help with?

3. How would you locate housing? How would you pay for it?

4. What specific skills do you need that you could learn while you are still in high school?

5. How can service providers help you? How can family members and friends help you?

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TABLE 8.2

Transition Planning Checklist for Postsecondary Education Opportunities

AGES 14-16: BEGIN TRANSITION PLANNING

- ✓ Begin career exploration activities. Consider participation in school counseling, vocational/career assessments, career fairs, meeting people in community, site visits, or special youth business and leadership programs.
- ✓ Begin self-advocacy coursework.

AGES 16-21: DEFINE CAREER/VOCATION GOALS

- ✓ Make sure that the IEP includes transition plans related to postsecondary education.
- ✓ Take high school courses that are required for entry into college, trade schools or careers of choice.
- ✓ Infuse job seeking and self-advocacy skills into school program.
- ✓ Take courses which include the development and practice of self-determination skills.
- ✓ Become involved in community-based work experiences, such as job tryouts, summer jobs, volunteering, or part time work.
- ✓ On an annual basis, assess interests and capabilities to match career goals.
- ✓ Identify and request entrance information for postsecondary institutions which offer training in careers of interest.
- ✓ Identify and take postsecondary entrance exams.
- ✓ Contact rehabilitation agency and/or the social security agency to determine eligibility for services and benefits.
- ✓ Visit selected postsecondary institution and assess programs and supports. Complete entrance applications.
- ✓ Ensure transition planning includes development of support services plan and "hand-off" of paperwork.

- For a youth who is deaf-blind, self-advocacy ahead is essential to achieving success in postsecondary education settings. Traveling around campus, securing textbooks, scheduling interpreters and notetakers all require ample skills and time to coordinate. Table 8.3 is a checklist designed to be used by youths who are deaf-blind, their families, and educators when visiting and choosing postsecondary education setting.

TABLE 8.3

Checklist For Youths Who Are Deaf-Blind: Assessing Postsecondary Education Supports[1]

Student's Name: _____

Name of School: _____

Name of School Contact Person: _____

Telephone/TDD Number: _____

Date of Assessment: _____

Have any students who are deaf-blind attended this school? Do any currently attend this school?
____ yes ____ no

(✓) CHECK ALL SERVICES THAT ARE AVAILABLE:

[ ] Large Print Materials
[ ] Notetakers
[ ] Reader Services
[ ] Alternate Test-Taking Methods
[ ] Interpreter Services
[ ] Braille Materials
[ ] Transportation Services
[ ] Reading Machines
[ ] Taped Textbooks
[ ] Counseling/Support Group
[ ] Other *(please describe)*

QUESTIONS ABOUT LARGE PRINT MATERIALS

1. *Are all course materials and books available in large print?*
   ____*yes* ____*no*

2. *How far in advance do students have to arrange for large-print materials?*

3. *Are students charged for having materials reproduced in large print?*
   ____*yes* ____*no*

4. *How much does this service cost?*

5. *Who does a student contact to arrange for materials in large print?*

Comments: _____

---

[1]*This checklist was adapted by the Helen Keller National Center - Technical Assistance Center (HKNC-TAC) from materials developed by L. Smith & J. Brodsky (undated). Inclusion, self-advocacy and a blueprint for effective transition to college with learning disabilities. Jericho, NY: Center for Learning Disabilities. Special thanks are extended to the postsecondary education students with Usher syndrome who reviewed this checklist and provided their suggestions for revisions.*

QUESTIONS ABOUT NOTETAKERS

1. *Are trained notetakers available through the school?*
   ____yes ____no

2. *Are students responsible for paying for notetaking services?*
   ____yes ____no

3. *How much do notetakers charge?*

4. *Who does a student contact about notetaker services?*

Comments: _____

QUESTIONS ABOUT READERS

1. *Are trained readers readily available through the school or community? ____yes ____no*

2. *Who is responsible for hiring and firing readers and dealing with any problems that arise?*

3. *Are students expected to pay for reading services?*
   ____yes ____no

4. *How much do reading services cost?*

Comments: _____

QUESTIONS ABOUT TAPED TEXTBOOKS

1. *Are all textbooks available on audio tape?*
   ____yes ____no

2. *How far in advance do students have to arrange to have books taped?*

3. *Are students charged for having books taped?*
   ____yes ____no

4. *How much do taped textbooks cost?*

Comments: _____

QUESTIONS ABOUT READING MACHINES

1. *What type of reading machines are available on campus?*

2. *How do students arrange to use a reading machine?*

Comments: _____

QUESTIONS ABOUT BRAILLE MATERIALS

1. *Are all reading materials available in Braille?*
   ____*yes* ____*no*

2. *How far in advance do students have to arrange for Braille materials?*

3. *Are students charged for having materials translated to Braille?*
   ____*yes* ____*no*

4. *How much does this service cost?*

Comments: _____

QUESTIONS ABOUT TRANSPORTATION SERVICES

1. *Are buses available for traveling between various parts of campus?*
   ____*yes* ____*no*

2. *If yes, do buses run on evenings, weekends, and holidays?*
   ____*yes* ____*no*

3. *Are there any other specialized transportation services available?*

Comments: _____

QUESTIONS ABOUT COUNSELING AND SUPPORT GROUPS

1. *Are counselors available who specialize in visual and hearing loss?*
   ____*yes* ____*no*

2. *Are students charged for counseling?*
   ____*yes* ____*no*

3. *Is there a waiting list for counseling services?*
   ____*yes* ____*no*

4. *Are there support groups for students who are deaf-blind?*
   ____*yes* ____*no*

5. *If yes, how often do the groups meet?*

6. *What kind of topics do the group members discuss?*

7. *Who does a student contact for more information about support groups?*

Comments: _____

References and Suggested Readings

HKNC, TAC News (1993, Fall) Transition Services and Personal Futures Planning, Sands Point, NY: HKNC-TAC.

Health Resource Center (Clearinghouse on Postsecondary Education for Individuals with Disabilities) Make the Most of Your Opportunities, Students Who Are Blind or Visually Impaired in Postsecondary Education, Students Who Are Deaf or hard of Hearing in Postsecondary Education, Learning Disabled Adults in Postsecondary Education, Transition Resource Guide.

Rusch, F. R., DeStefano, L., Chadsey-Rusch, J., Phelps, L. A., Szymanski, E., Transition From School To Adult Life, pg. 71-91. Sycamore Publishing Co., 1992.

Wagner, M. (1993). Trends in Postschool Outcomes of Youth with disabilities: Findings from the National Longitudinal Transition Study of Special Students. Paper prepared for the Transition Research Institute of Illinois, Project Director's Eighth Annual Meeting in Washington, DC, June 1993.

CHAPTER NINE

Expanding Social Opportunities for Youths Who Are Deaf-Blind

☞ *by JoAnn Enos*

WHAT TYPES OF RELATIONSHIPS SHOULD BE SUPPORTED FOR YOUTHS WHO ARE DEAF-BLIND IN TRANSITION?

- People with dual sensory impairment develop relationships in many of the same ways as do non-disabled individuals. These relationships can result in many types of associations -- from casual acquaintances, to group participators, to activity buddies, to best friends and more intimate relationships (Enos, 1995).

- Casual acquaintance describes a relationship that occurs as a result of similar needs and community presence. Adults become acquainted with their local hairstylists, bus drivers, auto mechanics, store clerks, postal clerks, neighbors, and bank tellers because of the frequency with which they need and use community services. Casual acquaintances may be abandoned when a need is no longer present (e.g., an individual joins a carpool instead of riding a bus) or when community presence is lessened or changed (e.g., a person retires or moves to a new community). The more community presence an individual experiences in meeting his or her daily needs, the more casual acquaintances the individual is likely to enjoy.

- Group participator describes a relationship in which two or more people who are members of clubs, classes, churches, teams, and other organizations meet for support of the event or activities. Relationships develop as a result of the group's events or activities. Although individuals are attracted to each other through mutual interests or values, without the mutual activity or events, the relationship might be abandoned or diminished. For example, individuals may socialize with each other during class breaks, during practice sessions for team sports, office parties, or church meetings, but they may have little contact with each other outside of these activities or events.

- Activity buddy describes a relationship in which two or more people jointly participate in activities each mutually enjoys, such as sporting events, music and theater events, and

dining. Individuals are initially attracted to each because of shared values and interests and actively seek opportunities to spend time together engaging in mutually enjoyable activities. These relationships generalize across multiple settings and opportunities for enjoying the activities.

- The final category of relationships, the best friend and intimate relationship, is internally focused and is prompted by a deeper appreciation of shared values and interests. This relationship extends beyond shared activities or events, and occurs when two or more people unconditionally care about the well-being of each other. It incorporates many factors: trust and acceptance, compromise, personal give-and-take, and open communication. It is bound by a more emotionally motivated bond. Over time, from this internal focus, long-term friendships and other intimate relationships develop.

What Steps are Necessary to Build Social Opportunities?

- **STEP ONE: Acknowledge and Accept the Needs of Individuals with Deaf-Blindness.** Some individuals will always need one-to-one, full-time support to develop and maintain relationships. For other individuals, as community presence, participation, and competence are increased, physical and mental challenges will decrease and natural supports will begin to emerge. Both formal and natural relationships help maintain interactions among the person with the dual sensory impairment and the non-disabled person peer or peers. Some youths who are deaf-blind may only need assistance in accessing information and relationships with a largely non-signing community. Support needs are as individualized as the likes and dislikes of the youth who is deaf-blind and the relationships and activities the individual pursues. The commonality within this group is the need for interdependence with others to access community environments and relationships with people in the environment.

- **STEP TWO: Assess the Quality and Quantity of Existing Relationships.** One strategy for assessing the quantity and quality of a youth's relationships is to borrow a visual mapping technique from personal futures planning (Mount, 1990). Service providers, family members, youths who are deaf-blind, and friends can use stick figure drawings, circles, and physical positioning of the figures to indicate the deaf-blind individual's current relationships.

- **STEP THREE: Increase and Enhance Relationships with Friends and Other Community Members.** Non-disabled adults meet other adults through places of work, neighborhoods, the organizations and clubs they attend, church, the leisure and recreation activities in which they participate, and through the friends they have already. They develop relationships with casual acquaintances, group participators, and activity buddies. Long-term friendships and other intimate relationships develop when they have opportunities to bond with each other over time. What bonds them to friends are the things they have in common--needs, values, interests, activities, and lifestyles.

  A non-disabled youth generally has the opportunity to access his or her community with no obstacles or limitations. A person can simply telephone the nearest health club, take a bus or drive to a local movie theater, or attend a social function through church or civic groups. On the other hand, youths with dual sensory impairment generally require more forethought and a considerable amount of planning to achieve the same outcome -- they probably do not drive, they probably need a TDD to make a telephone call, they may need assistive listening devices to enjoy a movie. Decreased community presence and participation decreases their opportunities to meet other youths and to develop relationships.

WHAT ARE SOME STRATEGIES FOR ENHANCING RELATIONSHIPS?

- The ideal, person-centered approach begins by assessing what the individual likes and dislikes, assessing current relationships, and building upon that information. Several approaches to developing and enhancing relationships should be considered: personal futures planning; community bridge-builders; modeling; and citizen or consumer advocacy (Enos, 1995).

- **Person-centered approaches involve the following steps:**
  - → Assessing individual likes and dislikes;
  - → Assessing current relationships;
  - → Using this information to create opportunities for new relationships and reinforce old relationships; and
  - → Providing supports to maintain and enhance relationships over time.

How can Relationships be Facilitated as Part of the Transition Process?

- There are opportunities for developing and enhancing relationships everywhere, in everyone's daily lives. For a youth with dual sensory impairment, it is up to service providers, family members, and friends to not overlook these occasions. The assumption that community members do not have enough experience or skills to interact and support youths who are deaf-blind denies everyone the chance for relationships that are both natural and spontaneous. Paid service providers can be utilized in more challenging roles as models for community members.

- Modeling for non-disabled persons to encourage comfort and skills in interacting with youths who are deaf-blind is a critical role for service providers and family members. It is the key to success in many relationships. **The Friends Project (1994) identified some service provider modeling practices that will foster community understanding and acceptance:**

  → **Introductions**

  - ✓ Treat each youth as an individual, and introduce him or her to other people on an individual basis.
  - ✓ Be sensitive to the use of labels such as "deaf-blind" or "dual sensory impaired".
  - ✓ Emphasize the characteristics the youth has in common with all people--we're all human beings with similar interests and needs!
  - ✓ Don't share information that highlights the individual's weaknesses or problems unless it is necessary for a specific situation.
  - ✓ Don't gossip about what is wrong with him or her. When information must be shared, do it as positively as possible.
  - ✓ Don't exaggerate the individual's need for professional help. Instead, emphasize informal community connections.
  - ✓ Think carefully about the situations in which you introduce individuals to the community, and be sure you are providing enough support for the experience to be successful for all parties.

→ **Connections**

- ✓ Teach by example.
- ✓ Model appropriate communication approaches.
- ✓ Treat the youth with the respect you would give anyone of the same age, in public and in private situations, and help him or her find ways to spend time with other people of the same age.
- ✓ Support youths who are deaf-blind in meeting and getting to know non-disabled people in regular community activities.
- ✓ Give individuals a chance to do what they can, and find ways to help them make a genuine contribution to others in the community.
- ✓ When a group or organization is receptive to including one person who is deaf-blind, don't expect them to include everyone else with dual sensory impairments.
- ✓ Think through individual needs and supports for each person.

→ **Ongoing Supports**

- ✓ Know that problems will arise.
- ✓ Trust people to solve them without professional intervention.
- ✓ When necessary, provide professional help as unobtrusively as possible.
- ✓ If a youth is difficult to understand or a challenge to develop connections with, provide lots of modeling, communication, and other supports without focusing on what doesn't work and why.
- ✓ Support members of the community by helping them learn what they need to know to be comfortable with the individual.

(Adapted from Amado et al., 1990)

How Can Youths who are Deaf-Blind Participate in Transition Planning?

▸ Youths who are deaf-blind can often be more involved in their transition planning activities if they are given the supports and strategies necessary to do so. The following questions may be useful to educators who are interested in teaching youths to think about and play a more active role in planning their futures.

Defining Your Vision

1. What are your greatest dreams?
2. What are your biggest fears?
3. What things might keep you from accomplishing your dreams?
4. How can service providers help you reach your goals?
5. How can family members and friends help you reach your goals?

Thinking About Postsecondary Education

1. What are your favorite classes? Why do you think you're successful in these classes?
2. What are your least favorite classes? Why do you think you're having difficulty in these classes?
3. How will the classes you are taking now help you reach your dreams?
4. Are you interested in attending college? How will it help you achieve your dreams?
5. What specific skills do you need that you could learn while you are still in high school?
6. How will you pay for college?
7. What support services do you think you will need in college? For example, interpreters, visual aids, audiological aids, orientation and mobility instruction? How do you feel about using these services?

Thinking About Employment

1. What job would you like to be doing two years from now? Five years from now? Ten years from now?
2. What kind of work experiences have you had? What kinds of things do you think you're good at? What are you not good at?
3. What skills will you need to do the kind of job you want to do? What kind of training or education do you need for this kind of job?
4. What things are important to you in a job? For example, salary, benefits, transportation, schedule, location, and personality of your boss?
5. What hobbies and interests do you have that might be related to a future job?
6. How can service providers help you get a job? How can family members and friends help you get a job?

- **Thinking About Living Arrangements**
  1. What does your dream house look like?
  2. What kind of chores do you do at home that will help you live more independently? What kind of chores do you need help with?
  3. How would you locate housing? How would you pay for it?
  4. What specific skills do you need that you could learn while you are still in high school?
  5. How can service providers help you? How can family members and friends help you?

- **Thinking About Financial/Income Needs**
  1. How do you manage your money now? How will you manage it after you leave high school?
  2. How much money do you need to reach your dreams?
  3. Are you familiar with SSI and Medicaid? Do you know how to apply for these services? Do you know who to contact if you have any questions about these services?

- **Thinking About Community Resources/Transportation/Medical Services**
  1. What support services are available to you as a youth who is deaf-blind? For example, TTY or TDD, assistive listening devices, low vision devices, interpreter services, orientation and mobility services, etc.?
  2. What support services are available to anyone who lives in your community? For example, food stamps, counseling services, public transportation, community recreation services, etc.?
  3. How would you find out about these and other support services?
  4. What kind of transportation do you use now? What will you use when you finish high school?
  5. How can service providers help you? How can family members and friends help you?

- **Thinking About Leisure/Recreation/Relationships**
  1. What do you like to do for fun? what are your hobbies and interests?
  2. Who are your friends? What characteristics are important to you in a friend?
  3. How do your friends help you? What do you wish they would do more or less of to help you?

4. Are there any activities you wish you could learn how to do? For example, bowling, swimming, skiing, knitting, painting, etc.?
5. Are there any high school activities you might like to get involved in?
6. How do you involve your friends and family members in your recreation activities?
7. What things prevent you from being involved in the recreation activities you are interested in? How can service providers help you? How can family members and friends help you?
8. How do you handle crisis or solve problems? What kind of things are stressful to you?
9. Whom would you go to if you had a problem or needed help?

Thinking About Medical/Advocacy/Legal Issues

1. Do you have a family doctor and dentist? How will you take care of your medical and health needs?
2. Do you have an eye and an ear doctor? Do you know what you need to do to take care of your eyes and ears?
3. Besides vision and hearing, do you have any medical needs that you will need to take care of?
4. If you run into a legal problem, how would you handle it? Who would you go to for help?
5. What do you know about first aid? Who would you contact in case of an emergency?
6. Which service providers can help you with medical or legal needs?
7. What kinds of insurance will you need, and how will you apply for it?

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CHAPTER TEN

Family Involvement in the Transition Process for Youths Who Are Deaf-Blind

☞ *by Kathleen McNulty*

WHY IS PARENT INVOLVEMENT SO IMPORTANT IN THE TRANSITION PROCESS?

- Parental involvement in planning transition services for youths who are deaf- blind is critical to the successful development and implementation of individualized plans (Giangreco, Cloninger, Mueller, Yuan & Ashworth, 1991; McNulty, Seiler, Covert & Everson, 1991). The complexity of dual sensory impairment and the individualized support services needed by these youths to attain community presence make it essential that parents and other family members be provided the opportunity to participate in the transition services process.

WHAT ROLES DO PARENTS PLAY IN THE TRANSITION PROCESS?

- There are at least four roles that parents and other family members can play. These roles include:
  - → (1) a parent or other family member who provides support and care for a youth, but who may not consistently attend or provide input to IEP teams;
  - → (2) an active member of an IEP team;
  - → (3) a membership or leadership role in a parent advocacy or support group; and
  - → (4) a membership or leadership role in a local- or state-level interagency team.

- Service providers must acknowledge that parents may *choose* to play any one or more of these roles. But parents can only choose roles *if* they are provided the information, skills, and support needed to choose and assume these roles.

What are Examples of Responsibilities Under Each Role?

- As an active member of an IEP team, a parent may be called upon to:
  - ✓ share important information about the youth;
  - ✓ assist the team in understanding the youth;
  - ✓ problem-solve with the team in a meaningful planning process;
  - ✓ support and compliment team members on the work they are doing;
  - ✓ argue and debate when programming is not appropriate;
  - ✓ advocate for additional services; and
  - ✓ display an understanding of federal and state regulations as they apply to the youth.

- Membership on a local- or state-level interagency team brings with it different responsibilities. Unlike IEP meetings, the focus of a local or state level interagency team is much broader. Parents may be called upon to:
  - ✓ advocate for systems change that impacts all families with transition-age youth who are deaf-blind;
  - ✓ provide a parent perspective on issues relating to transition;
  - ✓ work with other team members to develop services that integrate youths who are deaf-blind into the community;
  - ✓ assume a leadership role, such as chairperson of the team;
  - ✓ become knowledgeable of the service delivery system within their state; and
  - ✓ share the information they acquire as a team member with other parents.

- Parents involved in parent organizations or support groups may be called upon to:
  - ✓ support the mission and goals of the group;
  - ✓ attend meetings, network with other parents;
  - ✓ reach out to parents who are not active and involved;
  - ✓ assume a leadership role;
  - ✓ volunteer to perform organizational tasks (e.g. notetaking, writing correspondence, developing a "phone tree");
  - ✓ lobby for state and federal legislative change; and
  - ✓ organize formal training events or informal social gatherings.

How can Educators Assist Parents in Initiating and Attaining These Roles?

- Parents may choose a variety of roles and assume a variety of responsibilities. **Educators can assist parents in initiating and attaining these roles by observing the following guidelines:**

  → (1) recognize and respect parent roles
  → (2) provide parent education and support
  → (3) develop parent-professional partnerships
  → (4) adopt person-centered planning efforts
  → (5) advocate for a full range of family support service

- **The following considerations are offered to accompany these guidelines:**

→ (1) Recognize and Respect Parent Roles

Educators must recognize that there are a variety of roles parents can play. Some parents may choose to be parents and nothing more. Other parents may choose to be active, advocate members of the youth's IEP team. And still other parents may choose to be leaders of parent groups, interagency teams, or even paid, "professional" parent trainers. Parents may choose to play different roles at different points in their parenting "careers". Educators must be careful to accept without judgment whatever role or roles a parent has chosen to play.

→ (2) Provide Parent Education and Support

Supporting parents in a variety of roles requires educators to actively provide parents with a variety of training, membership, and leadership opportunities. There are numerous training resource available. For **example:**

- → the state and multi-state deaf-blind education projects which include parent training and support among their objectives;
- → the National Family Association for Deaf-Blind (NFADB), a national coalition of parents and family members of deaf-blind children who are dedicated to parent education and support, advocacy, and political lobbying;
- → the Hilton Perkins National Program which has been instrumental in developing deaf-blind parent groups in more than 20 states;
- → HKNC-TAC which provides an annual, national workshop on parent issues and transition services.

Parent education and support activities should be guided by these basic principles:

- ✓ Share facts and regulations on education and adult services through workshops, manuals, videotapes, brochures, and other mechanisms.
- ✓ Define and limit use of technical language and acronyms in training opportunities and during meetings.
- ✓ Whenever possible schedule trainings and meetings and provide child care and/or transportation supports so that parents can attend.
- ✓ Include parents in material development and agenda planning as well as in pre- and post-meeting communication loops.
- ✓ Touch base with parents through home visits, letters mailed home, and telephone calls before meetings to ensure their comfort with agendas, goals, participants, and terminology.
- ✓ Encourage parents to assume leadership positions whenever possible, ranging from IEP team members, to trainers of other parents, to chairs of parent groups or interagency groups.

→ (3) Develop Parent-Professional Partnerships

Parent-professional partnerships must be recognized not as simply a good thing to do, but as the best use of available resources. Parents do know the most about the youth and the family's dreams. They know how much money, time, energy, and other resources the family is willing and able to contribute to achieving transition goals for youths with dual sensory impairment. They know their local communities and the youth's informal support networks. They know the most about what has worked and what hasn't work for the youth across many years and multiple service providers. Parents also know and can organize other parents. As individuals and as groups, they can advocate for systemic changes in policies, personnel, and funding when paid service providers are stymied by their positions. Parental resources can be the missing link when planning and implementing transition service goals for youths with dual sensory impairment. As a result, parent-professional partnerships can develop and achieve higher quality transition goals in shorter periods of time than professionally-driven teams.

→ **(4) Adopt Person-Centered Planning Efforts**

Transition services are an opportune time to ensure person-centered planning activities because of the need for long-term and visionary thinking. Locations and times of meetings, presence of transition-age youths, invitations to other family members and community members, use of informal assessment techniques such as "profile maps," careful choice of wording, and design of forms can assist both family members and service providers in focusing on individuals.

→ **(5) Advocate for a Full Range of Family Support Services**

Finally, although most states provide some type of service called "family support", in most case, these services have been severely limited by budgetary constraints (Agosta & Bradley, 1985). Educators must assist parents in advocating for these much needed services. **They recommend the following guidelines in developing family support services:**

- → state budgets should include line items for family support services;
- → funds should be dispersed to localities with a per family cap;
- → case managers should be separated from service delivery and should be consumer-specific not agency-specific;
- → service must include a variety of local options (e.g., cash subsidy, reimbursement, direct provision of services, equipment, etc.); and
- → services must be monitored by parents as well as by church, business, consumer, and service provider representatives.

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